Title

Oncology outpatients and their caregivers

Author

Yeager, Katherine,

Publication Date

1993

Oncology Outpatients and their Caregivers: Their Knowledge and Experience of Pain

by

Katherine A. Yeager

THESIS

Submitted in partial satisfaction of the requirements for the degree of

MASTER OF SCIENCE

in

NURSING

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA

San Francisco

[redacted]

Date **University Librarian**

Degree Conferred: . . . 6-13-93 . . . .

Acknowledgements

I would like to thank Drs. Christine Miaskowski, Suzanne Dibble, and Margaret Wallhagen for their expertise and support. Special thanks go to Drs. Christine Miaskowski and Suzanne Dibble for the use of the data from their study "Oncology Outpatient Pain: Incidence and Morbidity Parameters."

I would also like to thank my husband, Dr. Hillard Weinstock, for his unending support and encouragement.

I would like to acknowledge the financial support of the Cancer Research Coordinating Committee of the University of California, and the Oncology Nursing Foundation, Purdue Fredrick Research Grant. I would also like to thank the American Cancer Society for the scholarship in cancer nursing that I received while completing this work.

Abstract

Two out of every three families have at least one family member diagnosed with cancer. With an increasing trend toward providing care to oncology patients in an ambulatory care setting, family members or friends of cancer patients often become caregivers. One symptom that affects many cancer patients and their caregivers is pain. Little research has been done to describe the knowledge and experience of the cancer patient in pain and their caregiver. Therefore, the purposes of this study were to determine : 1) if there was a significant difference in knowledge about pain between oncology outpatients with cancer-related pain and oncology outpatients who are pain-free; 2) if there was a relationship between selected patient characteristics (i.e. education, age, Karnofsky Performance status, pain intensity, pain duration, and gender) and the knowledge about pain of oncology outpatients with cancer-related pain; 3) if there was a difference in the knowledge about pain between caregivers of oncology outpatients with cancer-related pain and caregivers of oncology outpatients who are pain-free; 4) if there was a difference in the knowledge about pain between oncology outpatients with cancer-related pain and their caregivers; and 5) if there was a difference in the perception of the experience of pain between oncology outpatients with cancer-related pain and their caregivers. Three-hundred and sixty-eight oncology outpatients completed several self-report questionnaires including a Demographic Questionnaire; a Pain Experience Scale that measured the knowledge and experience of pain; and a Descriptive Numeric Rating Scale that measured pain intensity and duration. One-hundred and twenty-eight caregivers of oncology outpatients completed several self-report questionnaires including a Demographic Questionnaire and a Pain Experience Scale. Independent Student's t-test determined that: patients with cancer-related pain knew significantly more about pain than pain-free patients; and that caregivers of patients with cancer-related pain knew more about pain than caregivers of pain-free patients (all scores $p<.05$). To determine if selected patient characteristics correlated with the knowledge about pain, Pearson's Product Moment Correlation Coefficients were calculated. Age was negatively correlated with knowledge about pain. Educational level, daily pain, and days in pain were all positively correlated with knowledge about pain. Paired Student's t-test showed that there was no significant difference in the knowledge about pain between outpatients with cancer-related pain and their caregivers, but there was a significant difference in the perception of the experience of pain, with the caregivers viewing the experience more negatively than the patients. Results of this study emphasize the need for health care professionals to educate oncology outpatients and their caregivers about pain.

Table of Contents

List of Tables

List of Figures

Chapter 1: Introduction to the Problem

Two out of every three families will have at least one family member diagnosed with cancer (Woods, Lewis, & Ellison, 1989). The impact of cancer on a family is immense with many physical, psychosocial, and financial burdens associated with the disease and treatment (Ferrell, Ferrell, Rhiner, & Grant, 1991). With the increasing trend toward providing care to oncology patients in an ambulatory care setting, family members or friends of cancer patients often become caregivers whether they want to or not. Complex symptom management at home becomes a challenge for many patients and their families.

One symptom that may impact the caregiver of a cancer patient is pain. At least half of the patients diagnosed with cancer have pain (Bonica, 1985). However, most research studies on the incidence, severity, and types of cancer-related pain have been done with hospitalized patients (Cleeland, 1985). Limited research exists that describes the experience of the oncology outpatient who has cancer-related pain. At present, a limited amount is also known about cancer patients and their caregivers' knowledge about pain and their experience of pain (Austin, Cody, Eyres, Hefferin & Kransnow, 1986; Clipp & George, 1992; Curtis & Fernsler, 1989; Dar, Beach, Barden, & Cleeland, 1992; Ferrell, Cohen, Rhiner, & Rozek, 1991; Ferrell, Ferrell, Rhiner, & Grant, 1991; Ferrell, Rhiner, Cohen, &

Grant, 1991; Ferrell & Schneider, 1988). One can hypothesize that what patients and their caregivers know about pain and its treatment will influence how effectively they work together to relieve the pain. Also, how similarly they view the patient's experience of pain will not only affect their ability to relieve the pain, but may also affect how they live with and communicate about this experience. Research suggests that patients and caregivers are fearful of opiates and therefore undermedicate themselves or their family members (Austin et al., 1986, Ferrell & Schneider, 1988, Peteet, Tay, Cohen, & MacIntyre, 1986). If more information was known about individual patients' and their family members' knowledge and attitudes about cancer pain, we would be able to design and test specific targeted interventions to improve the treatment and management of this important clinical problem.

Purposes of the Study - the purposes of this study were to answer the following questions:

1. Is there a difference in knowledge about pain between oncology outpatients with cancer-related pain and oncology outpatients who are pain free?
2. What is the relationship between selected patient characteristics (i.e. education, age, Karnofsky Performance status, pain

intensity, pain duration, and gender) and the knowledge about pain of oncology outpatients with cancer-related pain?

3. Is there a difference in the knowledge about pain between caregivers of oncology outpatients with cancer-related pain and caregivers of oncology outpatients who are pain free?
4. Is there a difference in the knowledge about pain between oncology outpatients with cancer-related pain and their caregivers?
5. Is there a difference in the perception of the experience of pain between oncology outpatients with cancer-related pain and their caregivers?

Assumptions - the underlying assumptions in this study are as follows:

1. Pain is a multidimensional phenomenon.
2. Patients and their caregivers share the illness experience.

Definition of Terms - the following definition of terms will be used in this study:

1. Oncology outpatient - is a patient receiving outpatient treatment for cancer (not AIDS related) with any single or combination of the following modalities: 1) chemotherapy, 2) radiation therapy, 3) hormonal therapy, and/or 4) biotherapy.
2. Caregivers - is whoever the patient identifies as his/her primary

nonprofessional caregiver.

3. Cancer-related pain - is pain caused by cancer or cancer treatment, as determined by the medical record review and the patient's self-report.

4. Pain-free patients - are patients who report that they have not experienced any pain in the last month related to their cancer or cancer treatment or any other disease process.

5. Knowledge about pain - is the knowledge subscore of the Pain Experience Scale (PES). This portion of the questionnaire obtains information about an individual's knowledge of drug and nondrug treatments for pain, addiction, drug dependence, drug dosages, drug side-effects, and drug administration schedules (See Appendices A and E).

6. Experience of pain - is the experience subscore of the PES. This portion of the questionnaire obtains information about the experience of pain including the intensity of the pain, the amount of pain relief, the amount of distress related to the pain felt by the patient, and the amount of distress felt by the caregiver related to the patient's pain (See Appendices B and F).

Chapter II: Literature Review

Conceptual Framework

The multidimensional phenomenon of pain

Pain is a multidimensional phenomenon that consists of multiple components including: 1) a physiological component (i.e., the organic etiology of the pain); 2) a sensory component (i.e., attributes such as the intensity, location, and quality of the pain); 3) an affective component (i.e., depression and anxiety associated with pain); 4) a cognitive component (i.e., the manner in which the pain influences a person's thought processes or the manner in which a person views themself); 5) a behavioral component (i.e., pain behaviors such as activity level or analgesic intake); and 6) a sociocultural component (i.e., demographic characteristics, ethnic background, and/or family/social support). These six components do not contribute to the pain experience in isolation or independently. Rather, they are interrelated and influence one another to make pain a multidimensional experience for the individual (Ahles, Blanchard, & Ruckdeschel, 1983; Ahles & Martin, 1992; McGuire, 1987; McGuire, 1992).

The behavioral, cognitive, and sociocultural components of the pain experience will be examined in this study. Pain behaviors include the ways that patients express their discomfort, their changing activity patterns, and pain relief measures such as analgesic intake. One can assume that the patient's caregiver observes and reacts to the behavioral component and therefore shares this dimension of the pain experience. In addition, the caregiver may react to the behavioral manifestations of the patient's pain based on his or her own experience and knowledge of cancer pain and its management.

The cognitive component will be explored by evaluating the patient's knowledge about pain and pain management and how the patient views the pain experience.

The sociocultural component recognizes that cancer pain has a dramatic effect on family and social relationships. Factors in the sociocultural component such as family interactions, social support, and interpersonal communication affect the patients perception, expression of, and responses to the pain. Presumably, the patient and caregiver are interacting and the patient's pain may influence this interaction. This component will be explored by comparing the patient's and caregiver's knowledge about pain and pain management and how the patient and caregiver perceive the pain experience.

Literature Review

Pain has been identified as a major problem affecting millions of patients world wide (Bonica, 1985). The Oncology Nursing Society's Position Paper on

Cancer Pain describes the lack of information on the true impact of pain on the individual diagnosed with cancer (Spross, McGuire, & Schmidt, 1990). Now that many cancer patients are being treated in ambulatory care settings, the determination of the knowledge and experience of outpatients experiencing cancer-related pain warrants investigation. Family members and friends often serve as caregivers and may influence the care of the patient in pain. Therefore, determination of the knowledge and experience of caregivers of cancer outpatients in pain is equally important.

Pain experienced by oncology outpatients

A limited number of studies have been done on the pain experienced by ambulatory oncology patients (Ahles, Ruckdeschel, & Blanchard, 1984; Bressler, Hange, & McGuire, 1986; Daut & Cleeland, 1982; Peteet, et al., 1986; Portenoy et al.,1992). One study (Ahles et al., 1984) evaluated 208 consecutive ambulatory cancer patients to determine the prevalence of cancer-related pain in an outpatient setting and to distinguish between pain secondary to the cancer itself, as a result of cancer treatment, or to a noncancerous source. Results indicate that 33.5% of the patients had pain related to their cancer; 6.7% had pain related to cancer therapy; and 11% had noncancer-related pain. Patients with metastases had significantly more pain than patients without metastatic disease.

A limitation of this study was that the sample is obtained from one office setting.

A descriptive study evaluated 58 cancer outpatients experiencing pain in an attempt to characterize their pain experience (Bressler, et al., 1986). The mean pain intensity, measured by a Visual Analogue Scale at the time of interview, was 38.7 mm (range 0-100 mm) with a mean duration of 14.8 months. Pain intensity was not significantly related to age, sex, living arrangement, or performance status. The small sample size limits the generalizability of the study findings.

Daut and Cleeland (1982) described the frequency, severity, and disruptiveness of pain in 667 cancer patients. Patients with one of 6 types of cancer (breast, prostate, colon or rectum, or 3 gynecologic cancers) were evaluated. The sample included both outpatients and inpatients at a large comprehensive cancer center. Thirty to 40% of the patients without metastatic disease reported pain, whereas 47% to 64% of the patients with metastatic disease reported pain. Patients reported that current pain treatments and medications provided approximately 68% relief. Pain when present was often at least moderately severe and was felt to interfere with the patient's activity and enjoyment of life to a moderate or severe extent. While overall pain prevalence in a sample of inpatients and outpatients was evaluated, these data cannot be used to determine the prevalence of pain in an outpatient population.

In another study of cancer outpatients, investigators interviewed both the patients and their physicians (Peteet, et al., 1986). Thirty-seven out of 100 patients were assessed to have pain severe enough to require a narcotic or regular medication. Regular medication was not defined, but the data showed that five of the patients were taking nonnarcotic analgesics and the remainder of the patients were taking a narcotic analgesic. Interview data from 25 of the patient and doctor pairs demonstrated that patients tended to rate their pain as more severe than their physicians. The selection criteria may have biased the findings because patients were selected for participation based on medication usage rather than self-report of pain.

A prospective study of ambulatory patients with lung or colon cancer was done to determine the prevalence and characteristics of pain in these two groups (Portenoy et al., 1992). Telephone interviews determined that 39% of the patients with lung cancer and 29% of the patients with colon cancer experienced persistent or frequent cancer-related pain during the previous 2 weeks. Eighty-four percent of the patients interviewed by phone were seen in the clinic to determine pain characteristics. Thirteen percent of the patients reported noncancer-related pain and 33% of the patients reported cancer-related pain.

Pain intensity was assessed from three perspectives: 1) pain in general, 2) pain at its worst, and 3) pain at its least. Pain was measured on a 100 mm Visual Analogue Scale (VAS) and an eight item categorical scale. The mean pain in general for both groups of patients was 44.0 mm (S.D.=25.1) on the VAS and 4.9 (S.D.=1.2) on the categorical scale. A value of three on the categorical scale denotes weak pain, four denotes mild pain, five denotes moderate pain, and six denotes strong pain. Pain at its worst averaged 63.4 mm (S.D.=25.1) on the VAS and 5.8 (S.D.=1.3) on the categorical scale. Pain at its least averaged 18.1 mm (S.D.=20.6) on the VAS and 3.4 (S.D.=1.7) on the categorical scale. Intensity ratings were similar between patients with lung and colon cancer.

These studies (Ahles et al., 1984; Bressler, et al., 1986; Daut & Cleeland, 1982; Peteet, et al., 1986; Portenoy et al.,1992) evaluated the prevalence, characteristics, and management of pain in ambulatory oncology patients. However, none of the studies explored the patients' knowledge of pain and its treatment or presented information about the patients' caregivers knowledge of pain and its treatment.

Knowledge about pain in the general population

Public opinion about cancer pain is extremely important. In a study on public attitudes about cancer pain, 496 randomly selected people were interviewed over the telephone (Levin, Cleeland, & Dar, 1985). Twenty-four of the respondents had a history of cancer, while 359 had a relative or friend with cancer. No differences in attitudes toward cancer pain were found between those individuals with a personal or familial experience with cancer and those individuals whose knowledge of cancer came from other sources. Forty-eight percent of the participants viewed cancer as a very or extremely painful disease. Sixty-nine percent of the respondents agreed that cancer pain can get so bad that a person might consider suicide. In addition, the majority of the respondents were extremely concerned about the negative consequences of using narcotic analgesics for pain control. Fifty-eight percent of the participants reported that they would feel much concern or extreme concern about becoming mentally confused and 45% worried about the possibility of addiction. More information about the sample concerning their health history and experience as caregivers would have provided useful information. The random sample was selected from one midwestern state so the generalizability of this study is limited to that state. Since this was the only study of this nature found in the literature, replication is needed.

Prevalent public attitudes may lead cancer patients and their caregivers to assume that pain associated with cancer is inevitable and is difficult and sometimes dangerous to treat. In Cleeland's (1984) review article on the impact of pain on the patient with cancer, he discusses barriers to optimal cancer pain relief and describes what patients believe about pain. Many patients may refuse to follow carefully designed narcotic schedules and wait until the pain becomes unbearable before initiating treatment. Patients worry about taking strong drugs because they fear that the drugs will not be effective later in their illness when they feel they really will need them. They do not want to think of themselves as addicts or complainers but rather as "good patients" who can withstand pain. Sometimes patients worry that taking narcotics means that their disease has progressed and that death is inevitable. As Hill (1989) points out in his discussion of pain management, our society views drugs, in general, as very important in treating illness and solving a wide range of physical and emotional problems, but the public is confused about the use of narcotics. A major reason for inadequate drug treatment of cancer pain in a drug oriented society is the confusion of the public between legitimate narcotic use by patients in pain and the abuse of these drugs (Hill, 1989).

Knowledge of cancer patients about pain

No studies were found that have directly evaluated cancer patients' knowledge about pain. Several studies have evaluated how patients manage their pain and have provided useful information about patients' beliefs concerning pain treatment. One exploratory study looked at 75 cancer patients with chronic cancer pain (Ferrell & Schneider, 1988). The patients were interviewed in the hospital and seven to ten days after discharge to determine how the experience and intensity of pain differed in the hospital and at home. There were no significant differences in the quality or intensity of pain between the two settings, although this small sample did show trends of greater pain at home. Eighty-three percent of patients at home and 60% of the patients in the hospital took medications less frequently than ordered because of fears of addiction, fears of tolerance, misunderstanding dosages, and feeling that the pain could not be treated. Sixteen percent of the patients lived alone and 84% resided with family. No further information was provided about the patients' caregivers.

As part of the study by Peteet et al. (1986) discussed previously, a case report described a patient who reported taking less pain medicine than prescribed because of the fear of becoming addicted. Two other patients reported concerns about becoming tolerant to the effects of the medicine as the reason for not taking the amount of pain medication that the doctor had prescribed.

In another retrospective study, the home care charts of 96 terminally ill cancer patients were reviewed to determine pain management practices and whether patients followed their prescribed analgesic regimens (Austin, et al., 1986). Adjunctive treatments or medicines were not evaluated. Fifty percent of the patients who reported severe pain did not follow their prescribed analgesia regimen. Undertreatment occurred despite support, instruction, and education from the home care staff. Patients' reasons for not following the regimen generally fell into two categories: concerns about addiction and the desire to maintain personal control. Age or living arrangement were not related to the patients following their prescribed medication regimen. The correlation between a patient following their prescribed medication regimen and pain control was not significant, perhaps because this information, based on chart reviews, focused only on reported analgesic use. Also adjuvant treatments and medicine were not evaluated. No examination of the appropriateness of the medication prescribed was discussed. The role of the family caregiver in pain management was not evaluated.

Knowledge of caregivers of cancer patients about pain

Recent studies have shown that the caregiver, not just the patient, experiences the crisis of cancer. Work by Ferrell, Ferrell, Rhiner, and Grant (1991) described caregivers' knowledge about cancer-related pain and the experience of caring for a family member with cancer-related pain. A convenience sample of cancer patients requiring analgesic medication was used with the caregiver defined as the one family member most involved in the patient's care, as designated by the patient. A total of 85 caregivers in three settings (a community hospital, a home based hospice, and a cancer center) were compared. Both the patient and caregiver rated the intensity of the patient's pain. Caregivers, in all three settings, rated the patient's pain intensity significantly higher than the patient did (69.9 and 45.5, respectively, using a 0 to 100 scale). Caregivers rated the patient's pain as extremely distressing to the patient and also to themselves (78.4 and 77.3, respectively, using a 0 to 100 scale).

Some differences in caregivers' knowledge about pain were demonstrated among the care settings. Caregivers at the cancer center showed the least understanding of the principle of giving pain medication before pain becomes severe. Community hospital family members were less likely to believe that non-drug interventions would relieve pain. Patients in the hospice setting reported lower pain intensity scores than in other settings, and the caregivers reported lower levels of distress. Caregivers in the hospice setting reported feeling more supported and felt that they were doing the best job they could in managing the patient's pain.

This study focused on the caregivers' knowledge about cancer-related pain and did not compare it to the patients' knowledge. A major limitation of this study is that it compares caregivers from three settings, two of them being inpatient facilities. The caregiver's role in pain management in an inpatient facility compared to the role of the caregiver in a home based hospice may be quite different. In the home setting, the caregiver is often responsible for around the clock pain management, whereas the caregiver in the inpatient setting may share the patient care responsibilities with the nurse.

Recent qualitative research has suggested that cancer-related pain has a profound impact on the caregiver and has provided additional information about caregiver's knowledge of pain. In these studies ((Ferrell, Rhiner, Cohen, & Grant, 1991; Ferrell, Cohen, Rhiner, & Rozek, 1991), cancer patients in pain identified their caregiver as the family member most involved in their care. A total of 85 caregivers in three settings (a community hospital, a home based hospice, and a cancer center) were interviewed. From the interviews with the caregivers, themes were identified from caregiver responses to questions describing the patients' pain, their roles in pain management, and the administration of pain medication. The themes identified in response to the caregiver's description of pain included: anatomic description, hidden pain, family fear and suffering, and overwhelming/enduring pain. The themes concerning pain management and pain medication administration identified included: deciding what to give and when; the fear of addiction; night duty; reminding and encouraging; and being responsible to do "everything". Caregivers' roles in nonpharmacologic pain relief included the use of massage, oils, lotions, hot, cold, touch, distraction, and avoiding touch.

When the caregivers were asked what it is like having someone you love in pain, the themes identified included: helplessness, coping by denying feelings, and a wish for death. Caregivers also identified the need for doctors and nurses to do the following: explain the symptoms and treatments; discuss addiction concerns; offer hope and be there; discuss medication concerns; and listen and be honest. Caregivers spoke of nurses and doctors who hesitated to give medicines because of fears of addiction and the need for support in handling their own fears of addiction as family caregivers. Most caregivers desired to give more medication and said that giving the appropriate amount of medication would be a relief to patients as well as to themselves. These studies concluded that caregivers not only have a crucial role in drug and nondrug pain management but also share the patient's experience of cancer pain. The authors suggest that caregivers are influenced by such variables as: prior pain experience, cultural background, their relationship to the patient, and the meaning and understanding of the pain.

All these studies (Ferrell, Ferrell, Rhiner, & Grant, 1991; Ferrell, Rhiner, Cohen, & Grant, 1991; Ferrell, Cohen, Rhiner, & Rozek, 1991) discussed previously used caregivers from three settings. The information gained from this qualitative work would be more useful if it was known which caregivers were caring for the patient at home and which caregivers were with the patients in the hospital. Since the home setting included a hospice component, no information was provided about caregivers who care for nonterminal cancer outpatients in pain. None of the caregiver's knowledge about pain or their view of the pain experience was compared with that of the patients.

Patient and caregiver shared experience

Some of the studies that have compared patients' and caregivers' reports of pain focus on patients and their spouses (Dar et al., 1992; Clipp & George, 1992). In the study by Dar et al. (1992) patients and spouses were interviewed separately to assess beliefs about cancer pain and to examine how these beliefs might interact with patients' attitudes and behaviors related to their own pain treatment. The sample included 40 inpatients and outpatients with metastatic cancer, who had opiate analgesics prescribed for pain, as well as their spouses. The results suggest that patients underestimated the amount of distress their pain caused their spouses. Patients estimated their spouses' distress on average as 6.3, whereas spouses rated their own distress as 8.4 on a 0 to 10 scale . This difference was largest when male patients rated their spouses' distress.

In contrast to the study by Ferrell et. al. (1991), spouses did, on the average, accurately estimate the intensity of the patients' pain (patients average pain score was 5.45, and the spouses estimate of the patients' pain was 5.5). Despite this accurate assessment by the spouses, 60% of patients endorsed the statement "I sometimes try to hide my pain so my spouse will not get too upset". Concerning pain medication use, in 68% of the couples, the spouse rated the effect of the medication as being of shorter duration than did the patient. Forty-two percent of the spouses thought that the patient should only take narcotics when the pain was extreme and not on a regular basis as compared to 69% of the patients. Patient concerns about addiction, mental confusion, and increased tolerance were strongly associated with reports of reluctance to report pain and willingness to experience pain rather than take analgesics. Spouses also reported concerns about narcotic side effects and addiction. Overall, patients seemed satisfied with the way their spouses helped them to cope with the pain

(9.65 out of 10), while the spouses ranked themselves lower (8.15 out of 10). Spouses were more concerned about cancer pain than the patients. In 61% of the couples, the spouse ranked pain as a greater concern than the patient, whereas only 7.9% of the patients ranked pain as a greater concern than their spouses. Limitations of this study include a homogeneous rural midwestern sample of couples with long stable marriages. The sample also included a mixture of inpatients and outpatients.

Another study focused on patterns of responses between patients with cancer and their spouse caregivers to determine the reliability of spouse informants in research and clinical settings (Clipp & George, 1992). Thirty married couples, where the patient had either lung or colon cancer, were interviewed concurrently in their homes concerning patient functioning, psychologic distress, physical symptoms, caregiver perceptions of patient functioning, and marriage quality. The sample was selected from one large comprehensive cancer center. Couples had been married an average of 32 years.

There was high agreement between patient and caregiver responses about objective items such as activities of daily living (i.e., ability to dress and to use the toilet). Conversely, agreement was low on the subjective aspects of the cancer experience such as pain, confidence in treatment, amount of time thinking about the illness, and fear of the future. Spouse caregivers of cancer patients perceived the patients' illness experiences more negatively than did the patients. Specifically, caregivers reported that patients experienced more pain and more disease symptoms; had less ability to cope with the illness; spent more time thinking about the illness; were more discouraged; experienced more fear about the future; and were less confident about the treatment than the patients themselves reported. Limitations of this study include a small sample size of couples with long stable marriages from one southeast geographic area. The sample was also restricted to patients with two tumor types.

A descriptive study compared patients' and primary caregivers' view of the quality of life of hospice patients with cancer (Curtis & Fernsler, 1989). Twenty-three pairs of patient caregiver dyads were instructed to independently complete the Quality of Life Index. No differences in any area of quality of life were demonstrated except for the pain experience. This sample of primary caregivers, consisting primarily of family members and friends, reported significantly higher pain intensity scores for the patients than the patients did for themselves. The authors of this study suggest that hospice efforts to help patients and families communicate openly may be effective in all areas except pain. The findings of this study cannot be generalized beyond the study sample because of the small convenience sample of hospice patients.

Summary

Limited research has been done to determine the knowledge and experience of oncology outpatients who have cancer-related pain. Also, limited information exists about cancers patients' and their caregivers' knowledge of cancer pain. No studies have compared the knowledge of patients and their caregivers. No studies have compared the knowledge about pain of oncology outpatients with cancer-related pain and oncology outpatients without pain. Only a few studies have described the experience of the cancer patient in pain and the experience of their caregiver.

Research findings suggest that caregivers who witness the pain of their family members view the experience more negatively than the patients themselves who experience the pain (Clipp & George, 1992; Curtis & Fernsler, 1989). Although some information exists comparing married couples' experiences, no studies have compared the experiences of other types of caregivers, such as children, with the patients' experiences. Additionally, research in this area often has been limited to studies of patients with metastatic or terminal disease (Austin, et al., 1986; Dar, et al., 1992; Curtis and Fernsler, 1989). Patients in pain were often delimited to those who had been prescribed an analgesic medication. This type of delimitation defines the pain by the doctor prescribing the medicine, rather than by the patient's self report. Using this delimitation may eliminate a large number of cancer patients in pain and may effect the study findings and the interpretation of the results.

This study will focus only on oncology outpatients. Patients in pain will be defined solely by patients' self-reports of pain. A caregiver will include any person that the patient identifies as their primary caregiver. Important information will be gained by comparing the knowledge about pain of patients with cancer-related pain and cancer patients without pain, as well by comparing the knowledge of patients with cancer-related pain and their caregivers. Additionally, the perception of the experience of the patient with cancer pain and their caregiver's perception will be compared. This research will provide a basis for planning interventions to improve pain management in this population.

Chapter III: Methodology

Research Design

This study was part of a larger descriptive study examining the prevalence and characteristics of cancer and noncancer-related pain in an outpatient oncology population. This study determined if there were: 1) differences in knowledge about pain between patients with cancer-related pain and patients who are pain-free; 2) relationships between selected demographic characteristics (i.e. education, age, Karnofsky Performance status, pain intensity, pain duration and gender) and the knowledge about pain of oncology outpatients with cancer-related pain; 3) differences in knowledge about pain between caregivers of patients with cancer-related pain and caregivers of patients who are pain free; and 4) differences in the knowledge and the perception of the experience of pain between outpatient cancer patients with cancer-related pain and their caregivers.

Research Setting

The sample was recruited from 16 of the 35 sites that are part of the Oncology Nursing Research Network of California. This network was established in 1988 and is composed of over 150 oncology nurses. Nurses from 16 of the outpatient sites agreed to conduct this study at their site.

Sample Size and Criteria

A convenience sample of 435 adult (> 18 years) oncology outpatients was obtained. Inclusion criteria for the patients included: 1) adult oncology outpatients (> 18 years); 2) who were able to read, write, and understand English; 3) who agreed to participate and were able to give informed consent; 4) had a Karnofsky performance score of 50 or greater; and 5) were receiving outpatient treatment for cancer (not AIDS related) with any single or combination of the following modalities: 1) chemotherapy, 2) radiation, 3) hormonal therapy, and/or 4) biotherapy.

A convenience sample of caregivers, who accompanied the patient to the ambulatory care setting and was identified by the patient as a caregiver, was also recruited to participate in the study. Inclusion criteria for the caregiver included: 1) adult caregiver; 2) who were able to read, write, and understand English; and 3) who agreed to participate and were able to give informed consent.

Instruments

The instruments used in this study included a Demographic Questionnaire, a Medical Record Review Form, the Pain Experience Scale, the Karnofsky Performance Scale, and the Descriptive Numeric Rating Scale of Pain Intensity and Duration.

1. Demographic Questionnaire- (See Appendix C)

a. Description. The Demographic Questionnaire is an eight item self report questionnaire used to obtain information about age, gender, living arrangements, marital status, education level, ethnicity, employment status, and the patient's perception of the purpose of current cancer treatment of the patient. A similar form was used to obtain demographic information about the caregiver.

b. Scoring. Participants recorded their answers from a selection of possible responses.

c. Reliability and validity. Content validity was established by a panel of experts in oncology nursing. This instrument has been used in previous studies by the principal investigators.

2. Medical Record Review Form (see Appendix D)

a. Description. The Medical Record Review Form provides detailed information on date of initial cancer diagnosis, site of primary disease, sites and extent of metastases, previous therapy, type of surgery, current therapy, and reason for current therapy.

b. Scoring. The Medical Record Review Form was completed by either a nurse at the study site or by the Project Director based on a review of the patient's medical record and/or in consultation with the patient's nurse or physician.

c. Reliability and validity. The Medical Record Review Form was developed by a panel of experts in oncology nursing. Content validity was obtained by review and revisions of the instrument by the investigators. This instrument has been used previously by the principal investigators in another study.

3. Pain Experience Scale (PES)- (see Appendices A, B, E, and F)

a. Description. The PES was developed by Ferrell and Rhiner (personal correspondence, 1991). This 13 item instrument was modeled after tools that have been used extensively to measure the knowledge and attitudes of health care professionals. The PES measures an individual's knowledge of basic pain principles such as addiction, relief of pain, and routine analgesia. It also assesses an individual's perception of the experience of pain by asking for an estimate of the intensity of the patient's pain; an estimate of the amount of pain relief that the patient is experiencing; and an estimate of of how distressing the pain experience is for both the patient and the caregiver.

The tools used for the patient (see Appendices A & B) and the caregiver (see Appendices E & F) are identical except that one provided specific directions to the patient and the other provided specific directions to the caregiver.

Each item on the knowledge section of the PES contained a statement about cancer pain and/or pain relief. Below each item was a 100 mm linear analogue scale anchored on the left with the word "disagree" and on the right with the word "agree". Instructions ask the patient or caregiver to make an " X" on the line to indicate their level of agreement or disagreement with each statement.

The four items on the experience section of the PES contain statements about the amount of pain experienced by the patient, the amount of relief from pain experienced by the patient, the amount of distress the pain causes the patient, and the amount of distress the patient's pain causes the caregiver. Below each item was a 100 mm linear analogue scale anchored on the left with the words "no pain", "no relief", "none", and "none", respectively. The right side of the scale was anchored with the words "a great deal" for each item. Instructions asked the patient or caregiver to make an " X" on the line to indicate their response to each statement.

b. Scoring. The PES was scored using a Summa Sketch II. The PES includes nine items that measure an individual's knowledge about pain and four items that measure an individual's perception of the experience of pain. The total knowledge score for the PES was determined by summing the scores of each individual item (the range of scores for each item is 0 to 100) and dividing by 9. Items #2, 3, 5, 8, and 9 were reversed coded so that all scores would reflect the degree of correctness of the response on a 0 to 100 scale.

The total experience score for the PES was determined by summing the scores of each individual item (the range of scores for each item is 0 to 100) and dividing by 4. Items #11 was reversed coded so that higher scores would indicate increased pain, and increased distress.

c. Reliability and validity. The results of a series of psychometric analyses done with test-retest responses from caregivers (n=67) are as follows: content validity (CVI> .90), construct validity (ANOVA, $p < .05$), concurrent validity ($r > .6$, $p <. 05$), and factor analysis and test-retest reliability ($r >.8$, Ferrell, Ferrell, Rhiner, & Grant, 1991).

4. Karnofsky Performance Scale (KPS) - (see Appendix G)

a. Description. The KPS is designed to measure the patient's ability to accomplish normal activities of daily living or their need for help and nursing care (Karnofsky & Burchenal, 1949). The KPS consists of a series of 8 items for ranking functional status from 30 (disability, with hospitalization needed) to 100 (adequate health status, with no complaints or evidence of disease).

b. Scoring- the patient was asked to "circle the number that best describes your abilities at the present time" on a scale from 30 to 100 in increments of 10. A score of 100% indicates that the individual feels normal and has no complaints or symptoms. A score of 30 indicates that the individual is severely disabled and needs to be hospitalized.

c. Reliability and Validity: Reliability and construct validity of the KPS have been established and it has been shown to be a global indicator of the functional status of patients with cancer (Schag, Heinrich, & Ganz, 1984; & Yates, Chalmer, & McKegney, 1980). In one study, performance status was rated by two physicians and the patients themselves (n=100) using the KPS and the Eastern Cooperative Group (ECOG) scale to evaluate reliability and validity of the instruments (Conill, Verger, & Salamero, 1990). Correlations were significant between the two physicians scores (r= .75 for KPS, .76 for ECOG, p< .001) and between physicians and patients rating (.65 for KPS, and .59 for ECOG, p< .001).

To test for construct validity, the KPS has also been compared to single-item physical quality of life scales, such as the Katz ADL scale. The results of this comparison found the KPS to be unbiased and complete, with a correlation coefficient of .35 (Mor, LaLiberte, Morris, & Wiemann, 1984). Schag, Heinrich, & Ganz (1984) studied 293 cancer patients to test the validity of the KPS. They reported that the KPS had very good interrater reliability among physicians (r= .89).

5. Descriptive Numeric Rating Scale of Pain Intensity and Duration (see Appendix H)

a. Description. The Descriptive Numeric Rating Scales of Pain Intensity and Duration each contain a horizontal, row of numbers ranging from 0 to 10 with verbal descriptors below several of the numbers (i.e., 0 = none, 2 = mild, 5 = moderate, 8 = severe, and 10 = excruciating).

b. Scoring. Patients were asked to rate the intensity of their pain using the descriptive numeric rating scale from 0 (no pain) to 10 (excruciating pain) at the time of completing the questionnaire (i.e., pain right now). In addition, patients were asked to report the following on the Numeric Rating Scale: average daily pain; current worse pain; and current pain at its least.

To obtain information on duration of pain, patients were asked to indicate: 1) how many days (0 to 7) out of a typical week do you currently experience significant cancer-related pain (i.e., pain that interferes with your mood and/or your activities)?; and 2) on those days when you have significant cancer-related pain, how many hours of the day (0 to 24) does it currently last?

c) Reliability and Validity. The validity of a numeric scale is difficult to establish since there is no absolute measure of pain intensity (Wewers & Lowe, 1990). Since pain is not a static phenomenon, reliability of a pain rating scale is also difficult to establish (Huskisson, 1974). However, a number of researchers have found that numeric rating scales are reliable and valid measures of perceived pain intensity (Downie et al., 1978; & Ohnhaus, & Adler, 1975). In addition, a numeric rating scale is a simple robust, and sensitive measure of pain intensity and has yielded reproducible results with many types of patients in many setting (Huskisson, 1983).

Data Collection Procedures

Human subjects approval was obtained from the Committee on Human

Research at the University of California, San Francisco, California.

Nurses at all 16 sites were trained in data collection procedures by the study's co-principal investigator. After obtaining informed consent (see Appendix I), patients were asked to complete the Patient Information Questionnaire (PIQ) and return it to the nurse for review. The PIQ contains the Demographic Questionnaire, the Pain Experience Scale, and the Karnofsky Performance Scale. The final questions on the PIQ asked the patient to report whether they had experienced cancer or non-cancer-related pain in the past month (see Appendix J). The nurses reviewed the PIQ for completeness and based on the patient's responses to the last two questions and gave the patient the Cancer Related Pain Questionnaire (CRPQ) if the patient had cancer-related pain. The patient was instructed to complete the questionnaire in the practice setting or take it home and bring it back at their next scheduled appointment. The CRPQ contains the Descriptive Numeric Rating Scales for pain intensity and duration. For the analysis of this study, only question 5 from the CRPQ was used (see Appendix H).

The patients were asked if they had a person who had accompanied them to the site who they identified as their caregiver. The caregiver, if available, was asked to participate in the study. After obtaining informed consent (see Appendix

K), the caregiver was instructed to independently complete the Caregiver Information Questionnaire (CIQ) and return it to the nurse for review. The CIQ contained the Demographic Questionnaire and the Pain Experience Scale.

Data Analysis

Data were analyzed using the CRUNCH Statistical Software Package with a Dell Computer. Appropriate descriptive statistics including frequency distributions was generated.

Independent Student's t-tests were done to determine: 1) if there is a difference in the knowledge about pain between oncology outpatients with cancer-related pain and oncology outpatients who are pain-free and 2) if there is a difference in the knowledge about pain between caregivers of oncology outpatients with cancer-related pain and caregivers of oncology outpatients who are pain free.

In order to determine if there is a relationship between selected patient characteristics (i.e., education, age, pain intensity, pain duration, and Karnofsky Performance Status) and the knowledge about pain of patients with cancer-related pain, Pearson's Product Moment Correlation coefficients were calculated. In addition, an independent Student's t-test was used to determine if there is a difference between gender and the knowledge about pain of patients with cancer-related pain.

In order to determine if there is a difference in the knowledge about pain or in the perception of the experience of pain between oncology outpatients with cancer-related pain and their caregivers, paired Student's t-tests was performed. Interpretation of the study's finding will be accomplished by carefully reviewing the data in light of previous research findings and clinical experience.

Chapter IV: Results

1. Patient Demographics

a. Patients with Cancer-Related Pain

Participants (n=200) were primarily caucasian (88.0%), middle aged (mean=53.8 years, S.D.=14, range 19 to 80), with an average of two years of college education. The majority of the participants were female (58.0%), married or partnered (64.8%), and did not live alone (82.7%). Many of the patients were retired (24.5%) or disabled (27.0%), although 22.0% worked full time. The demographic characteristics of the patients with cancer-related pain are summarized in Table 1.

These patients were diagnosed with a variety of cancers. The most common cancers included breast cancer (23.0%), colon/rectal cancer (12.5%), lung cancer (12.5%), prostate cancer (6.5%), non-hodgkins lymphoma (6.5%), and ovarian cancer (6.0%). Current therapy for these patients included chemotherapy (62.9%), radiation (14.7%), hormonal therapy (5.6%), and biotherapy (.5%), with other patients receiving various combinations of those four treatment modalities. The medical record review revealed that the reason for current therapy for the majority of the patients was control of the disease (45.7%), followed by cure (34.2%), and palliation (18.6%). Patients had an average

Karnofsky Performance Score of 78.1. Most of the patients had metastatic disease (70.4%) and had had a surgical procedure as part of their previous therapy (64.0%).

b. Pain-free Patients.

Pain-free patients (n=169) were primarily caucasian (84.3%), middle aged (mean=59.5 years, S.D.=14, range 22 to 82), with an average of 2 years of college education. The majority of participants were female (51.8%), were married or partnered (58.9%) and did not live alone (69.6%). Many of the patients were retired (38.6%) or disabled (12.1%), although 22.3% worked full-time. The demographic characteristics of the pain-free patients are summarized in Table 1.

These patients were diagnosed with a variety of cancers. The most common cancers included breast cancer (20.7%), colon/rectal cancer (20.1%), lung cancer (9.5%), prostate cancer (13.6%), non-hodgkins lymphoma (7.7%), and ovarian cancer (3.6%). Current therapy for these patients included chemotherapy (61.6%), radiation (18.9%), and hormonal therapy (8.5%), with other patients receiving various combinations of treatment modalities. The medical record review showed that the reason for current therapy for the majority of patients was to cure the disease (54.5%), followed by control (32.9%), and palliation (11.4%). Patients had an average Karnofsky Performance Score of 87.5. Most of the patients had metastatic disease (57.8%) and had had a surgical procedure as part of their previous therapy (76.6%).

c. Comparison of the Demographic Characteristics of Patients with Cancer-Related Pain and the Pain-Free Patients

Significant differences were demonstrated between patients with cancer-related pain and pain-free patients in the areas of: age, Karnofsky Performance Status (KPS), living arrangements, employment status, and the presence of metastatic disease. These data are summarized in Table 2.

Patients with cancer-related pain were significantly younger (mean= 53.8 years) than pain-free patients (mean= 59.5 years, t= -3.87, p= 0.0001). Patients with cancer-related pain had significantly lower KPS scores (mean= 78.1) than pain-free patients (mean= 87.5, t=-6.74, p<0.0001). Patients with cancer-related pain were more likely to live with someone else (82.7%) than pain-free patients (69.6%, X^2=7.99, p=.0047). Patients with cancer-related pain were more likely to have metastasis (70.4%) than pain-free patients (57.8%, X^2= 5.68, p=.017). Patients with cancer-related pain were more likely to be disabled (30.7%) than pain-free patients (14.0%, X^2=11.43, p=.0007).

2. Caregiver Demographics

a. Caregivers of Patients with Cancer-Related Pain

The caregivers of the patients with cancer-related pain (n=86) were primarily caucasian (92.9%), middle aged (mean= 52.9 years, S.D.=14, range 15 to 83), with an average of 2 years of college education. The majority of these caregivers were female (63.6%) and were married or partnered (82.6%). Most of the caregivers' relationship to the patient was as a spouse or a partner (74.4%), although 10.5% were children of the patient, and 5.8% were a friend of the patient. Many of the caregivers were employed full-time (37.2%), although 25.6% were retired, and 10.5% were unemployed. The majority of the caregivers denied a loss of salary, wages, or benefits due to caring (58.3%), although 13.9% did report losses, and 27.8% were not employed. The demographic characteristics of the caregivers of patients with cancer-related pain are summarized in Table 3.

b. Caregivers of Pain-free Patients.

The caregivers of the pain-free patients (n=42) were primarily caucasian (92.9%), middle aged (mean= 54.9 years, S.D.=14, range 28 to 78), with an average of 2 years of college education. The majority of the caregivers were female (52.4%) and were married or partnered (97.6%). Most of the caregivers relationship to the patient was as a spouse or a partner (78.6%), although 9.5%

were children of the patient, and 7.1% were parents of the patient. Many of the caregivers were retired (43.9%), although 26.8% were employed full-time, and 9.8% were unemployed. Most of the caregivers denied a loss of salary, wages, or benefits due to caring (44.8%), although 27.6% did report a loss, and 27.6% were not employed. The demographic characteristics of the caregivers of pain-free patients are summarized in Table 3.

c. Comparison of the Demographic Characteristics of Caregivers of Patients with Cancer-Related Pain and the Caregivers of Pain-Free Patients

No significant differences were demonstrated between the caregivers of the patients with cancer-related pain and the caregivers of the pain-free patients in the areas of: age, education, gender, relationship to patient, employment status, or losses due to caring. These data are summarized in Table 4.

3. Prevalence of Cancer-Related Pain in Oncology Outpatients:

Two hundred oncology outpatients (54.2%) experienced cancer related pain in the past month, while 169 oncology outpatients (45.8%) were pain-free.

4. Types and Causes of Cancer-Related Pain

Based on an analysis of the medical record data and the data from the patient questionnaires, cancer-related pain was categorized as somatic, visceral, deafferentation, or somatic/deafferentation in origin. The largest percentage of patients had pain of somatic origin (48.9%), followed by deafferentation (27.8%), visceral (19.6%), and somatic/deafferentation (3.8%). The two most frequent causes of pain were bone metastasis (29.3%) and post-surgical pain syndromes (22.0%). The remaining causes are summarized in Table 5.

5. Intensity and Duration of Pain

The patients rated the intensity of their pain on a 0 to 10 scale. Scores were reported for pain right now (mean= 2.2), average daily pain (mean= 3.6), current worse pain (mean= 6.5), and current pain at its least (mean= 1.6). Patients reported experiencing a mean of 4.2 days of the week in a significant amount of pain and a mean of 9.2 hours of the day in significant pain. Table 6 summarizes the patients' ratings of their pain intensity and duration.

6. Study Purpose 1: Differences in Knowledge about Pain between Oncology Outpatients with Cancer-Related Pain and Oncology Outpatients who are Pain Free

An independent Student's t-test was done to determine if there was a difference in overall knowledge about pain between patients with cancer-related pain and pain-free patients. Results demonstrate that patients who experienced cancer-related pain scored significantly higher on the knowledge subscore of the

PES (mean=57.3) compared to patients who were pain free (mean= 52.8, t= 2.878, p= .0043). These data are illustrated in Figure 1.

Each of the individual items on the knowledge section of the PES were analyzed, using an independent Student's t-test, to determine if there were statistically significant differences in the scores on each question between patients with cancer-related pain and pain-free patients. The results are summarized in Table 7. Patients with cancer-related pain agreed less strongly with the statement "cancer pain can be effectively relieved" than did pain-free patients (t=-2.16, p=.031). Patients with cancer-related pain scored significantly higher (i.e., responded that they disagreed with the statement) than pain-free patients on the following statements: "pain medicine should only be given when pain is severe" (t=3.74, p=.0002); "most cancer patients in pain will become psychologically addicted to the medicine over time" (t=2.48, p=.014); and "patients are often given too much pain medicine" (t=2.65, p=.008).

7. Study Purpose 2: Relationship between Knowledge about Pain Of Oncology Outpatients with Cancer-Related Pain and the Selected Patient Characteristics.

To determine if knowledge about pain in oncology outpatients with cancer-related pain was related to age, education, Karnofsky Performance Score, and pain intensity ratings and/or pain duration ratings, Pearson's Product Moment

Correlation Coefficients were calculated. The results are summarized in Table 8.

Age was negatively correlated with the knowledge score (p<.0001). Years of education, average daily pain, and average number of days in significant pain were positively correlated with the knowledge score (p=.0008, p=.023, p=.0083 respectively). As determined by an independent Student's t-test, females scored (mean=57.41) significantly higher than males (mean=51.67, t=3.990, p=.0001) on the knowledge subscale of the PES.

8. Study Purpose 3: Differences in Knowledge about Pain between Caregivers of Oncology Outpatients with Cancer-Related Pain and Caregivers of Oncology Outpatients who are Pain Free

An independent Student's t-test was done to determine if there was a statistically significant difference in knowledge about pain between caregivers of patients with cancer-related pain and caregivers of pain-free patients. Results demonstrate that caregivers of patients with cancer-related pain scored significantly higher on the knowledge section of the PES (mean=56.52) compared to caregivers of patients who were pain-free (mean=50.52, t=2.389, p=.0187). These data are illustrated in Figure 2.

Each of the individual items on the knowledge section of the PES were analyzed using an independent Student's t-test to determine if there were statistically significant differences between the caregivers of oncology outpatients with cancer-related pain and the caregivers of oncology outpatients who were pain-free. The results are summarized in Table 9. Caregivers of patients with cancer-related pain were more likely to correctly disagree with the statement that stated that cancer patients in pain will become addicted to the medicine over time (t=2.57, p=.0115). There were no statistically significant differences between the responses of the two groups on any of the other items on the knowledge subscale of the PES.

9. Study Purpose 4: Differences in Knowledge about Pain between Oncology Outpatients with Cancer-Related Pain and their Caregivers

A paired Student's t-test demonstrated that there was no statistically significant difference in the total knowledge subscale scores of the PES between patients with cancer-related pain (mean= 58.9) and their caregivers (mean= 57.6; t=58.8, p>.05). These findings are illustrated in Figure 3.

10. Study Purpose 5: Differences in the Perception of the Experience of Pain between Oncology Outpatients with Cancer-Related Pain and their Caregivers

Paired Student's t-tests determined that there were significant differences in the perception of the experience of pain between patients with cancer-related pain and their caregivers. As illustrated in Figure 4, caregivers viewed the overall experience more negatively than did the patients (t= 4.08, p= .0002).

When analyzing the individual statements of the experience section of the PES, caregivers of patients with cancer-related pain reported that patients had significantly higher levels of pain than did the patients (t=2.23, p=.0279; Figure 5). Caregivers reported that the patients experienced slightly less pain relief than did the patients (t =.71, p>.05; Figure 6). Caregivers reported that the patients experienced significantly more distress from the pain than the patients reported (t=4.11, p=.0001; Figure 7). Caregivers reported significantly greater distress from the patients' pain for themselves than the patients reported for their caregiver (t=4.05, p=.0001; Figure 8). The comparisons between the patients and the caregivers scores for each of the four statements on the experience section of the PES are reported in Table 10.

Chapter V: Discussion

This study was undertaken because information is needed about the amount of knowledge oncology outpatients with and without pain as well as their caregivers have about cancer pain and its management. These data can be used to guide healthcare providers in developing more effective strategies to educate patients and their caregivers. This large scale study is the first to evaluate the knowledge about pain of oncology outpatients and their caregivers. This is an extremely important and growing population of patients since much of oncology treatment now takes place in outpatient settings.

Overall, the patients who participated in this study were well educated and relatively young. Of particular interest is that patients with cancer-related pain, in this study, were younger, had lower Karnofsky Performance scores, were more likely to live with someone else, and were more likely to have metastasis than the pain-free patients. These data suggest that pain in a younger oncology outpatient population may be associated with more extensive and debilitating disease.

In this outpatient sample (N=369), 54.2% of the patients experienced cancer-related pain. The pain prevalence data of this study are consistent with previous studies (Ahles et al., 1984; Bressler et al., 1986; Daut & Cleeland, 1982;

Peteet et al., 1986; Portenoy et al., 1992). Patients' pain intensity scores (average daily pain, mean= 3.61) were fairly high, and are consistent with previously published reports (Daut & Cleeland, 1982; Portenoy et al., 1992).

Caregivers who participated in this study, were also well educated and relatively young. Twice as many of the patients with cancer-related pain had a caregiver that participated in the study (N=86) as compared to pain-free patients (N=42). The higher number of caregivers in the pain group may be related to the poorer performance status in the pain population and their need for assistance in getting to the outpatient setting. The majority of the caregivers were spouses, although the sample also contained children, significant others, friends and parents.

Although, patients with cancer-related pain scored significantly higher on the knowledge subscale of the PES than pain-free patients, total knowledge scores were not very high for either group (57.31 for patients with cancer-related pain; compared to 52.76 for the pain-free patients). With the best possible score being 100, these data demonstrate that oncology outpatients whether or not they are experiencing pain have a limited amount of knowledge about the management of cancer pain.

As Table 11 shows, both patients with cancer-related pain and pain-free patients scored highest on the following statements: (agreed that) cancer pain can be relieved; (disagreed that) pain medicines should be used only when pain is severe; and (agreed that) treatments other than medicines were effective in relieving pain. Both groups had mid-range scores (approximately 50) on statements that evaluated knowledge about the concepts of physical dependance and psychological addiction. These mid-range responses may indicate that patients were uncertain about the meaning of these concepts. The lowest scores, in both groups of patients, were on statements about the dosing and scheduling of medications. This latter finding supports Cleeland's (1984) discussion of barriers to optimal cancer pain relief where he describes patients in pain who wait until the pain becomes unbearable before initiating treatment and patients who worry about taking strong drugs because they fear these drugs will not be effective later in their illness.

Pain-free patients indicated a higher level of agreement with the statement that cancer pain can be effectively relieved perhaps because they have not had to deal with pain and its management or because they may have experienced successful pain relief in the past. Patients with cancer-related pain indicated a higher level of disagreement with the statement that pain medicine should be given only when pain is severe perhaps because they had learned it was better to take their pain medication before the pain became too severe. Patients with cancer-related pain understood the concept of psychological addiction better than pain-free patients perhaps because the patients with pain had not felt they had become "addicted" to their medicine or had received education about the meaning of psychological addiction. Patients with cancer-related pain indicated a higher level of disagreement with the statement that patients are often given too much pain medicine perhaps because they had not received enough pain medication to adequately relieve their pain. This suggestion is supported by the relatively high pain intensity ratings as well as the significant duration of pain these patients were experiencing.

In analyzing the relationship between knowledge about pain and selected patient characteristics, females had higher knowledge scores than males, younger patients had higher scores, and patients with more education had higher scores. In addition, patients with higher average daily pain intensities and higher number of days in pain had significantly higher knowledge scores. In contrast, no relationship was found between knowledge scores and the ratings of the pain right now, pain at its worst, or pain at its least. These data suggest that certain demographics characteristics as well as pain characteristics are associated with an individuals' knowledge about pain. Additional research with a larger sample is needed to determine the exact relationship between these characteristics and knowledge about pain management.

Although, caregivers of patients with cancer-related pain scored significantly higher than pain-free patients, total knowledge subscale scores were not very high for either group (56.52 for caregivers of patients with cancer-related pain; compared to 50.52 for the caregivers of pain-free patients).

As Table 11 shows, caregivers of patients with cancer-related pain and caregivers of pain-free patients both scored highest on the following statements: (agreed that) cancer pain can be relieved; (disagreed that) pain medicines should be used only when pain is severe; and (agreed that) treatments other than medicines were effective in relieving pain. Both groups had mid-range scores (approximately 50) on statements that evaluated knowledge physical dependance and psychological addiction. These mid-range responses may indicate that they were uncertain about the meaning of these concepts. The lowest scores in both groups were on the statements about the dosing and scheduling of medications. Of note, the pattern of responses of the caregivers is almost identical to the patients responses discussed previously.

Concerning differences between caregivers of patients with cancer-related pain and caregivers of pain-free patients, the only differences in responses between the two groups of caregivers was the caregivers of patients with cancer-related pain understood the concept of addiction better than caregivers of pain-free patients.

There was no significant difference between the knowledge scores of patients with cancer-related pain (mean=58.9) compared to their caregivers (mean=57.6). Since the scores of the patients with cancer-related pain and their caregivers were significantly higher than the patients and caregivers in the pain-free group, these findings suggest that the patients with cancer-related pain and their caregivers share their knowledge about pain with each other.

In contrast to the similarities in the knowledge scores, caregivers in this study rated the experience of the patients' pain more negatively than did the patients. These data on the pain experience are consistent with previous reports (Clipp and George, 1992; Dar et al., 1992). As seen in the study by Ferrell, Ferrell, Rhiner, and Grant (1991), the caregivers in this study, rated the patients overall pain intensity significantly higher (46.3), than did the patients (37.8). Overall, the pain relief scores reported by both the patient (50) and the caregivers (46.8; with 0=no relief and 100 = a great deal) were poor. There was no significant difference in the pain relief scores between the patients and the caregivers. However, caregivers rated the patients distress and their own distress from the pain significantly higher than did the patients. These findings suggest that patients and caregivers have different perceptions of the pain experience. Additional research is needed to determine when and how and if patients and caregivers communicate with each other about the pain experience and the impact of the experience on their lives.

The data suggest that caregivers are experiencing a high level of distress when caring for a patient experiencing pain. These data are consistent with previous qualitative data on the caregiver experience (Ferrell, et al., 1991a, Ferrell, et al., 1991b). It should be noted that Ferrell's work was done primarily with terminally ill patients. The majority of the patients in this study were receiving outpatient treatment to cure or control their disease. The significant amount of distress related to pain that the caregiver experiences seems to cut across all types of patient populations. Additional work is needed to determine the long term impact of this type of distress on a caregiver.

The exact etiology of the caregivers distress is not known but the distress could possible be related in part to the patients pain, the patient's cancer diagnosis, their responsibilities as a caregiver, or their lack of knowledge about pain. This level of caregiver distress is alarming because this is the group of people who will most likely serve as the patients' caregivers when they become more debilitated and when the caregivers responsibilities no doubt will increase. Because many cancer patients are being treated on a outpatient basis, support by a caregiver is essential to the patients functioning. Surprisingly, only 13.9% of the caregivers reported losses of work due to being a caregiver, although 27.8% were not employed.

Limitations

Several limitations of this study need to be acknowledged. Patients with or without pain were not matched for age, sex, or diagnosis. Caregivers were also not matched by age, sex, employment status, or relationship to the patient, although there were no differences in their demographic characteristics. An important limitation of this study is that this well educated sample cannot be generalized to patients or caregivers with less education. An additional limitation is that the sample was mainly Caucasian so that the results can not be generalized to other ethnic groups. In addition, patients with adequate pain relief from analgesics or non-pharmacologic measures to control pain may have self-reported that they were not in pain. Thus, the sample of pain patients may not be an accurate representation of the total sample of oncology outpatients experiencing cancer-related pain.

Implications for practice:

First these findings show that pain must be treated more effectively, since patients continue to experience significant amounts of pain and are not receiving adequate amounts of pain relief. In addition, education for patients and caregivers about pain and pain management is needed. The findings demonstrate that both patients and their caregivers agree that cancer pain can be effectively relieved. Healthcare providers must capitalize on this belief and give the patients and caregivers tools to relieve the patient's pain.

To determine specific targeted teaching strategies, the rankings in Table 11 can be used to categorize the scores into three response groups: knowledgeable (score 70 to 100), uncertain (69 to 45), and incorrect (<45). The highest priority in educating both patients and caregivers should be in the areas of dosing and scheduling medications. Next teaching priorities should include information on side effects (e.g., pain medicines effect on breathing), addiction, and dependence. Healthcare providers should reinforce that cancer pain can be effectively relieved with pharmacologic as well as nonpharmacological methods.

When teaching patients and caregivers, it must be recognized that pain-free patients and their caregivers will most likely have less knowledge about pain than patients who have been experiencing cancer-related pain and their caregivers. Since Bonica (1985) suggests that between 50 to 70 percent of all cancer patients will experience pain at some point during the disease trajectory, all cancer patients and their caregivers should receive education on pain and pain management.

In regard to the level of distress of the caregiver of patients with cancer-related pain, studies need to be designed to explore why these caregivers view the pain experience more negatively than the patient. In addition, healthcare providers must develop specific interventions to foster open communication between patients and their caregivers about the patients' pain. Caregivers need support to help them manage their distress and plan for the future. Improvements in communication from health care providers about pain would possibly provide role models for communication for the patients and caregivers.

Implications for research:

Based on the results of this study, additional areas of investigation would include:

1. A study to determine how and when patients and caregivers communicate about pain.
2. An intervention study to determine the most effective way to educate oncology patients and their caregivers about pain and pain management.

3. Additional studies with patients from different ethnic groups, of different ages, and different levels of education to determine their knowledge about pain and pain management.

References

Ahles, T.A., Blanchard, E.B., & Ruckdeschel, J.C. (1983). The multidimensional nature of cancer related pain. Pain, 17, 277-288.

Ahles, T.A., & Martin, J. B. (1992). Cancer pain: A multidimensional perspective. The Hospice Journal, 8, 25-48.

Ahles, T.A., Ruckdeschel, J.C., & Blanchard, E.B. (1984). Cancer-related pain: Prevalence in an outpatient setting as a function of stage of disease and type of cancer. Journal of Psychosomatic Research, 28, 115-119.

Austin, C., Cody, C., Eyres, P., Hefferin, E., & Krasnow, R. (1986). Hospice home care pain management. Cancer Nursing, 9, 58-65.

Bonica, J.J. (1985). Treatment of cancer pain: Current status and future needs. In Fields, H.L., Dubner, R., & Cervero, F. (Eds.), Advances in pain research and therapy, vol. 9, proceedings of the fourth world Congress on pain. (pp. 589-616). New York: Raven Press.

Bressler, L.R., Hange, P.A., & McGuire, D.B. (1986). Characterization of the pain experience in a sample of cancer outpatients. Oncology Nursing Forum, 13, 51-55.

Cleeland, C. (1984). The impact of pain on the patient with cancer. Cancer, 58, 2635-2641.

Cleeland, C. (1985). Measurement and prevalence of pain in cancer. Seminars in Oncology Nursing, 1, 87-92.

Clipp, E., & George, L. (1992). Patients with cancer and their spouse caregivers. Cancer, 58, 1074-1079.

Conill, C., Verger, E., & Salamero, M. (1990). Performance status assessment in cancer patients. Cancer, 65, 1864-1866.

Curtis, A.E., & Fernsler, J.I. (1989). Quality of life of oncology hospice patients: a comparison of patient and primary caregiver reports. Oncology Nursing Forum, 16, 49-53.

Dar, R., Beach, C., Barden, P., & Cleeland, C. (1992). Cancer pain in the marital system: A study of patients and their spouses. Journal of Pain and Symptom Management, 7, 87-93.

Daut, R.L., & Cleeland, C.S. (1982). The prevalence and severity of pain in cancer. Cancer, 50,1913-1918.

Downie, W.W., Leatham, P.A., Rhind, V.M., Wright, V., Branco, J.A., & Anderson, J.A. (1978). Studies with pain rating scales. Annals of the Rheumatic Diseases, 37(4), 378-381.

Ferrell, B.R., Cohen, M.Z., Rhiner, M., & Rozek, A. (1991). Pain as a metaphor for illness. Part II: Family caregivers' management of pain.

Oncology Nursing Forum, 18, 1315-1321.

Ferrell, B.R., Ferrell, B.A., Rhiner, M., & Grant, M. (1991). Family factors influencing cancer pain management. Postgraduate Journal of Medicine, 67 Suppl 2, S64-S69.

Ferrell, B.R., Rhiner, M., Cohen, M.Z., & Grant, M. (1991). Pain as a metaphor for illness. Part I: Impact of cancer pain on family caregivers. Oncology Nursing Forum, 18, 1303-1309.

Ferrell, B.R., & Schneider, C. (1988). Experience and management of cancer pain at home. Cancer Nursing, 11, 84-90.

Hill, C.S., Jr. (1989). Pain management in a drug-oriented society, Cancer, 63, 2383-2386.

Huskisson, E.C. (1974). Measurements of pain. Lancet, 2, 1127-1131.

Karnofsky, D., & Burchenal, J. (1949). The clinical evaluation of chemotherapeutic agents in cancer. In C. M. Macleod (Ed.), Evaluation of Chemotherapeutic agents. New York: Columbia University Press.

Levin, D., Cleeland, C., & Dar, R. (1985). Public attitudes toward cancer pain. Cancer, 56, 2337-2339.

McGuire, D.B. (1992). Comprehensive and multidimensional assessment and measurement of pain. Journal of Pain and Symptom Management, 7, 312-

319.

McGuire, D.B. (1987). The multidimensional phenomenon of cancer pain. In D. B. Mcguire & C.H. Yarbro (Eds.), Cancer Pain Management (pp.1-20). Orlando, FL: Grune and Stratton.

Mor, V., LaLiberte, L., Morris, J., & Wiemann, M. (1984). The karnofsky performance status scale. Cancer, 53, 2002-2007.

Ohnhaus, E.E., & Adler, R. (1975). Methodologic problems in the measurement of pain: A comparison between the verbal rating and the visual analogue scale. Pain, 1(4), 379-384.

Peteet, J., Tay, V., Cohen, G., & MacIntyre, J. (1986). Patient characteristics and treatment in an outpatient cancer population. Cancer, 57, 1259-1265.

Portenoy, R.K., Miransky, J., Thaler, H.T., Hornung, J., Bianchi, C., Cibas-Kong, I., Feldhamer, E., Lewis, F., Matamoros, I., Sugar, M.Z., Oliviera, A. P., Kemeny, N.E., & Foley, K. M. (1992). Pain in ambulatory patients with lung or colon cancer. Cancer, 70, 1616-1624.

Schag, C., Heinrich, R. & Ganz, P. A. (1984). Karnofsky performance status revisited: Reliability, validity, and guidelines. Journal of Clinical Oncology, 2, 187-193.

Spross, J.A., McGuire, D.B., & Schmidt, R.M. (1990). Oncology Nursing Society

Position Paper on Cancer Pain, Pittsburgh, Pa: Oncology Nursing Society.

Wewers, M.E., & Lowe, N.K. (1990). A critical review of visual analogue scales in the measurement of clinical phenomena. Research in Nursing and Health, 13(4), 227-236.

Woods, N.F., Lewis, F.M., & Ellison, E.S. (1989). Living with cancer. Family experiences. Cancer Nursing, 12, 28-33.

Yates, J., Chalmer, B., & Mckegney, F. (1980). Evaluation of patients with advanced cancer using the Karnofsky performance status. Cancer, 45, 2220-2224.

Table 1
Demographic Data on Patients with Cancer-Related Pain and Patients Who Are Pain-Free

Characteristic	**Pain (n=200)**		**Pain-free (n=169)**	
	MEAN	SD	MEAN	SD
AGE(years)	53.8	14.0	59.5	14.0
EDUCATION (years)	14.1	2.9	13.8	3.3
KARNOFSKY PERFORMANCE SCALE	78.1	13.8	87.5	12.4
	n	(%)	n	(%)
GENDER				
Female	166	58.0	87	51.8
Male	84	42.0	81	48.2
LIVE ALONE				
Yes	34	17.3	51	30.4
No	163	82.7	117	69.6
MARITAL STATUS				
Married/status	129	64.8	99	58.9
Widowed	14	7.0	27	16.1
Divorced	23	11.6	17	10.1
Separated	3	1.5	4	2.4
Never Married	23	11.6	17	10.1
Unmarr./live together	7	3.5	4	2.4

Table 1 (Continued)
Patient Demographic Data

Characteristic	**Pain (n=200)**		**Pain-free (n=169)**	
	n	(%)	n	(%)
ETHNICITY				
Caucasian	176	88.0	140	84.3
Black	6	3.0	9	5.4
Hispanic	7	3.5	9	5.4
American Indian	2	1.0	4	2.4
Mixed Ethnic Background	5	2.5	2	1.2
Asian or Pacific Islander	3	1.5	0	0.0
Eurasian	0	0.0	1	0.6
Other	1	0.5	1	0.6
Employment				
Retired	49	24.5	64	38.6
Full-Time	44	22.0	37	22.3
Disability	54	27.0	20	12.1
Homemaker	13	6.5	18	10.8
Part-Time	19	9.5	14	8.4
Self-employed	10	5.0	8	4.8
Unemployed due to pain	6	3.0	2	1.2
Unemployed due to other reasons	5	2.5	3	1.8

Table 1 (Continued)
Patient Demographic Data

Characteristic	**Pain (n=200)**		**Pain-free (n=169)**	
	n	(%)	n	(%)
CANCER DIAGNOSIS				
Breast	46	23.0	35	20.7
Colon/rectal	25	12.5	34	20.1
Other	23	11.5	21	12.4
Lung	25	12.5	16	9.5
Prostate	13	6.5	23	13.6
Non-Hodgkins Lymphoma	13	6.5	13	7.7
Ovarian	12	6.0	6	3.6
Hodgkins	10	5.0	3	1.8
Head and Neck	6	3.0	4	2.4
Multiple Myeloma	8	4.0	0	0.0
Acute Leukemia	3	1.5	2	1.2
Uterine	3	1.5	2	1.2
Bladder	2	1.0	2	1.2
CLL	1	0.5	3	1.8
Brain	4	2.0	0	0.0
Cervical	1	0.5	2	1.2
Gastric	1	0.5	2	1.2
Esophageal	2	1.0	0	0.0
Malignant melanoma	1	0.5	1	0.6
Pancreatic	1	0.5	0	0.0
METASTATIC DISEASE				
Yes	138	70.4	96	57.8
No	58	29.6	70	42.2

Table 1 (Continued)
Patient Demographic Data

Variable	**Pain (n=200)**		**Pain-free (n=169)**	
	n	(%)	n	(%)
CURRENT THERAPY				
Chemotherapy(CTX)	124	62.9	101	61.6
Radiation(XRT)	29	14.7	31	18.9
Hormonal(HRT)	11	5.6	14	8.5
XRT & CTX	12	6.1	8	4.9
XRT & HRT	5	2.5	5	3.1
CTX & HRT	4	2.0	1	0.6
Biotherapy	1	0.5	0	0.0
Biotherapy & CTX	2	1.0	1	0.6
Other	9	4.6	9	1.8
REASON FOR CURRENT THERAPY (Medical Record Review)				
Cure	68	34.2	91	54.5
Control	91	45.7	55	32.9
Palliation	37	18.6	19	11.4
Other	3	1.5	2	1.2

Table 2

Comparison of Patient Demographic Characteristics by Pain Status

Characteristic	Pain (n=200)	Pain-free (n=169)	Statistic	Significance
	Mean (SD)	Mean (SD)	(t)	(p)
AGE(years)	53.8 (14.0)	59.5 (14.0)	-3.87	.0001
EDUCATION (years)	14.1 (2.9)	13.8 (3.3)	0.67	NS
KARNOFSKY PERFORMANCE STATUS	78.1 (13.8)	87.5 (12.4)	-6.74	<.0001
	n(%)	n(%)	(X^2)	(p)
GENDER				
Female	116 (58.0)	87 (51.8)	1.19	NS
Male	84 (42.0)	81 (48.2)		
LIVE ALONE				
Yes	34 (17.3)	51 (30.4)	7.99	.0047
No	163 (82.7)	117 (69.6)		
MARITAL STATUS				
Married/status	136 (68.3)	103 (61.3)	1.69	NS
other	63 (31.7)	65 (38.7)		

Table 2 (Continued)
Comparison of Patient Demographic Characteristics by Pain Status

Characteristic	**Pain (n=200)**	**Pain-free (n=169)**	**Statistic**	**Significance**
	n(%)	**n(%)**	**(X^2)**	**(p)**
ETHNICITY				
Caucasian	176 (88)	140 (84.3)	0.75	NS
Others	24 (12)	26 (15.7)		
EMPLOYMENT				
Employed/Retired	122 (69.3)	123 (86.0)	11.43	.007
Disability	54 (30.7)	20 (14.0)		
METASTATIC DISEASE				
Yes	138 (70.4)	96 (57.8)	5.68	.017
No	58 (29.6)	70 (42.2)		
SURGERY				
Yes	121 (68.4)	119 (76.3)	2.21	NS
No	56 (31.6)	37 (23.7)		
REASON FOR THERAPY				
Cure	68 (34.7)	91 (55.2)	14.40	.0001
Control/palliation	128 (65.3)	74 (44.8)		

NS=Not significant

Table 3

Demographic Data on Caregivers of Patients with Cancer-Related Pain and Patients Who Are Pain Free

Characteristic	Pain (n=86)		Pain-free (n=42)	
	MEAN	SD	MEAN	SD
AGE(years)	52.9	14	54.9	14
EDUCATION (years)	13.8	2.8	13.7	3.5
	n	(%)	n	(%)
GENDER				
Female	55	63.6	22	52.4
Male	31	36.1	20	47.6
RELATIONSHIP TO PATIENT				
Spouse/partner	64	74.4	33	78.6
Significant other	2	2.3	1	2.4
Child	9	10.5	4	9.5
Parent	3	3.5	3	7.1
Other Relative	3	3.5	1	2.4
Friend	5	5.8	0	0.0
MARITAL STATUS				
Married/status	71	82.6	41	97.6
Widowed	1	1.2	0	0.0
Divorced	9	10.5	1	2.4
Separated	0	0.0	0	0.0
Never Married	2	2.3	0	0.0
Unmarr./live together	3	3.5	0	0.0

Table 3 (Continued)
Caregiver Demographic Data

Characteristic	**Pain (n=86)**		**Pain-free (n=42)**	
	n	(%)	n	(%)
ETHNICITY				
Caucasian	79	92.9	39	92.9
Black	1	1.2	0	0.0
Hispanic	2	2.4	2	4.8
American Indian	0	0.0	0	0.0
Mixed Ethnic Background	2	2.4	0	0.0
Asian or Pacific Islander	0	0.0	0	0.0
Eurasian	0	0.0	0	0.0
Other	1	1.2	1	2.4
Employment				
Retired	22	25.6	18	43.9
Full-Time	32	37.2	11	26.8
Part-Time	7	8.1	2	4.9
Other	15	17.4	4	9.8
Leave of Absence	1	1.2	2	4.9
Unemployed	9	10.5	4	9.8
Losses due to caring				
Yes	10	13.9	8	27.6
No	42	58.3	13	44.8
Not employed	20	27.8	8	27.6

Table 4

Comparison of Caregiver Demographic Characteristics by Pain Status

Characteristic	**Pain (n=86)**	**Pain-free (n=42)**	**Statistic**	**Significance**
	Mean (SD)	**Mean (SD)**	**(t)**	**(p)**
AGE(years)	52.9 (14.1)	54.9 (13.8)	-.74	NS
EDUCATION (years)	13.8 (2.8)	13.7 (3.5)	-.21	NS
	n(%)	**n(%)**	**(X^2)**	**(p)**
GENDER				
Female	55 (64)	22 (52.4)	1.13	NS
Male	31 (36)	20 (47.6)		
RELATIONSHIP TO PATIENT				
Spouse/partner	66 (76.7)	34 (81)	.10	NS
Other	20 (23.3)	8 (19)		
EMPLOYMENT STATUS				
Employed	39 (45.3)	13 (31.7)	4.44	NS
Other	25 (29.1)	10 (24.4)		
Retired	22 (25.6)	18 (43.9)		

Table 4 (Continued)

Comparison of Caregiver Demographic Characteristics by Pain Status

Characteristic	Pain (n=86)	Pain-free (n=42)	Statistic	Significance
	n(%)	n(%)	(X^2)	(p)
LOSSES DUE TO CARING				
Yes	10 (13.9)	8 (27.6)	2.87	NS
No	42 (58.3)	13 (44.8)		
Not employed	20 (27.8)	8 (27.6)		

NS=not significant

Table 5
Types and Causes of Cancer-Related Pain

TYPE OF PAIN	n	%
Somatic	65	48.9
Visceral	26	19.6
Deafferentation pain	37	27.8
Somatic/deafferentation	5	3.8

CAUSE OF PAIN	n	%
Bone Metastasis	36	29.3
Post-surgical pain syndrome	27	22.0
Pressure of thoracic and abdominal visceral	23	18.7
Mucositis from CTX	6	4.9
Infiltration of nerve root	5	4.1
CTX induced neuropathy	4	3.3
Compression fracture	3	2.4
Headache	3	2.4
Invasion of soft tissue	2	1.6
Post incisional	2	1.6
Related to pneumonitis	2	1.6
Related to mucositis	2	1.6
Blister from chemotherapy	1	0.8
Chest tube insertion	1	0.8
Related to skin burns	1	0.8
Adhesions	1	0.8
KB lesions	1	0.8
Sacral plexopathy	1	0.8
Related to fatigue	1	0.8
Abdominal cramps past CTX	1	0.8

Table 6
Description of Pain

DESCRIPTION	N	MEAN	STANDARD DEVIATION
Pain right now	137	2.2	2.2
Average daily pain	129	3.6	2.2
Current worse pain	130	6.5	2.5
Current pain at its least	129	1.6	1.8
Days a week experiencing pain	140	4.2	2.8
Hours of day the pain lasts	133	9.2	9.1

Table 7
Knowledge Scores of Patients with Cancer-Related Pain and Patients Who are Pain-Free

Statement	Correct Response	Cancer Pain X ± S.E.M. (n)	Pain Free x ± S.E.M (n)	Statistic
1. Cancer pain can be effectively relieved.	Agree	79.1 ± 2.1 (185)	85.4 ± 1.9 (148)	t=-2.16 p=.031
2. Pain medicines should be given only when pain is severe.	Disagree	69.6 ± 2.8 (191)	53.1 ± 3.5 (156)	t=3.74 p=.0002
3. Addiction refers to a person's desire to use drugs for their psychic effects rather than for medical use of relieving pain. Most cancer patients on pain medicines will become psychologically addicted to the medicines over time.	Disagree	62.1 ± 3.0 (184)	50.7 ± 3.47 (146)	t=2.48 p=.014
4. Drug dependence means that a person would go through withdrawal if a pain medicine was stopped. Most cancer patients on pain medicine will become physically dependant on the medicines over time.	Agree	49.9 ± 3.0 (187)	57.8 ± 3.3 (142)	t=-1.74 NS

* Scores are reported as means ± S.E.M. of correct responses (range 0 to 100) to the knowledge statements of the PES. NS= Not significant

Table 7
Knowledge Scores of Patients with Cancer-Related Pain and Patients who are Pain Free (Continued)

Statement	Correct Response	Cancer Pain x ± S.E.M. (n)	Pain Free x ± S.E.M (n)	Statistic
5. It is better to give the lowest amount of medicines possible early on so that larger doses will be available later if pain increases.	Disagree	23.2 ± 2.4 (193)	19.8 ± 2.5 (149)	t=.0959 NS
6. It is better to give pain medications around the clock (on a schedule) rather than only when needed.	Agree	33.7 ± 2.9 (190)	30.4 ± 3.1 (149)	t=.765 NS
7. Treatments other than medications (such as massage, heat, relaxation) can be effective for relieving pain.	Agree	78.6 ± 2.3 (189)	76.4 ± 2.7 (143)	t=.630 NS
8. Pain medicines can often interfere with breathing.	Disagree	54.3 ± 3.2 (160)	53.1 ± 3.5 (129)	t=.263 NS
9. Patients are often given too much pain medicine.	Disagree	60.3 ± 3.0 (175)	48.1 ± 3.5 (136)	t=2.65 p=.008

* Scores are reported as means ± S.E.M. of correct responses (range 0 to 100) to the knowledge statements of the PES. NS= Not Significant

Table 8
Relationship between Demographic Characteristics and Knowledge of Pain of Patients with Cancer-Related Pain

	KNOWLEDGE SUBSCORE	
	PEARSON CORRELATION COEFFICIENT	p VALUE
AGE	-0.26	<0.0001
EDUCATION	0.18	0.0008
KARNOFSKY	-0.10	NS
PAIN NOW	0.05	NS
DAILY PAIN	0.21	0.03
WORST PAIN	0.16	NS
LEAST PAIN	0.03	NS
DAYS IN PAIN	0.24	0.0083
HOURS IN PAIN	0.12	NS

NS= not significant, p>.05

Table 9
Knowledge Scores of Caregivers of Patients with Cancer-Related Pain and Caregivers of Patients who are Pain-free

Statement	Correct Response	Cancer Pain $\bar{x}$ ± S.E.M. (n)	Pain Free $\bar{x}$ ± S.E.M (n)	Statistic
1. Cancer pain can be effectively relieved.	Agree	69.8 ± 3.7 (82)	72.7 ± 5.2 (36)	t=-.449 NS
2. Pain medicines should be given only when pain is severe.	Disagree	76.2 ± 3.7 (83)	66.0 ± 6.7 (36)	t=1.44 NS
3. Addiction refers to a person's desire to use drugs for their psychic effects rather than for medical use of relieving pain. Most cancer patients on pain medicines will become psychologically addicted to the medicine over time.	Disagree	64.0 ± 4.3 (81)	43.5 ± 6.7 (34)	t=2.57 p=.0115
4. Drug dependence means that a person would go through withdrawal if a pain medicine was stopped. Most cancer patients on pain medicines will become physically dependant on the medicines over time.	Agree	54.6 ± 4.5 (78)	59.5 ± 6.6 (35)	t=-0.61 NS

* Scores are reported as means ± S.E.M. of correct responses (range 0 to 100) to the knowledge statements of the PES. NS= Not Significant

Table 9
Knowledge Scores of Caregivers of Patients with Cancer-Related Pain and Caregivers of Patients who are Pain-free (continued)

Statement	Correct Response	Cancer Pain x ± S.E.M. (n)	Pain Free x ± S.E.M (n)	Statistic
5. It is better to give the lowest amount of medicines possible early on so that larger doses will be available later if pain increases.	Disagree	19.7 ± 3.2 (83)	17.5 ± 4.5 (37)	t=.338 NS
6. It is better to give pain medications around the clock (on a schedule) rather than only when needed.	Agree	41.0 ± 4.8 (80)	29.0 ± 6.1 (38)	t=.1.49 NS
7. Treatments other than medications (such as massage, heat, relaxation) can be effective for relieving pain.	Agree	76.0 ± 3.5 (80)	83.2 ± 4.3 (38)	t=-1.22 NS
8. Pain medicines can often interfere with breathing.	Disagree	44.3 ± 4.5 (68)	34.9 ± 6.6 (30)	t=1.18 NS
9. Patients are often given too much pain medicine.	Disagree	58.9 ± 4.6 (71)	45.3 ± 6.8 (35)	t=1.69 NS

* Scores are reported as means ± S.E.M. of correct responses (range 0 to 100) to the knowledge statements of the PES. NS= Not Significant

Table 10
Comparisons of the Experience of Pain between Oncology Outpatients with Cancer-Related Pain and their Caregivers

Statement	Range	Patients x ± S.E.M. (n)	Care-givers x ± S.E.M (n)	Statistic
10. How much pain are you (is the patient) currently having?	0 = no pain 100 = a great deal	37.8 ± 3.9 (65)	46.3 ± 3.9 (65)	t=2.25 p=.028
11. How much relief are you (is the patient) currently receiving?	0= no relief 100 = a great deal	50.0 ± 4.3 (65)	46.8 ± 4.2 (65)	t=0.71 NS
12. How distressing is your pain for you (the patient's pain for the patient)?	0 = none 100 = a great deal	48.3 ± 4.6 (69)	64.5 ± 4.0 (146)	t=4.11 p=.0001
13. How distressing is your pain to your family member (the patient's pain to you)?	0 = none 100 = a great deal	52.2 ± 4.7 (66)	71.0 ± 4.2 (66)	t=4.05 p=.0001

* Scores are reported as means ± S.E.M. of correct responses (range 0 to 100) to the experience statements of the PES. NS= Not Significant

Table 11

Ranking of the Correct Responses of Patients and Caregivers to the Knowledge Statements of the PES

Statement Rank	Patients with Cancer-Related Pain (score)	Pain-Free Patients (score)	Caregivers of Patients with Cancer-Related Pain (score)	Caregivers of Pain-Free Patients (score)
1	#1 (79.1)	#1 (85.4)	#2 (76.2)	#7 (83.2)
2	#7 (78.6)	#7 (76.4)	#7 (76.0	#1 (72.7)
3	#2 (69.6)	#4 (57.8)	#1 (69.8)	#2 (66.0)
4	#3 (62.1)	#2 & #8 (53.1)	#3 (64.0)	#4 (59.5)
5	#9 (60.3)	#3 (50.7)	#9 (58.9)	#9 (45.3)
6	#8 (54.3)	#9 (48.1)	#4 (54.6)	#3 (43.5)
7	#4 (49.9)	#6 (30.4)	#8 (44.3)	#8 (34.9)
8	#6 (33.7)	#5 (19.8)	#6 (41.0)	#6 (29.0)
9	#5 (23.2)		#5 (19.7)	#5 (17.5)

1. Cancer pain can be effectively relieved.
2. Pain medicines should be given only when pain is severe.
3. Addiction refers to a person's desire to use drugs for their psychic effects rather than for medical use of relieving pain. Most cancer patients on pain medicines will become psychologically addicted to the medicine over time.
4. Drug dependence means that a person would go through withdrawal if a pain medicine was stopped. Most cancer patients on pain medicines will become physically dependant on the medicines over time.
5. It is better to give the lowest amount of medicine possible early on so that larger doses will be available later if pain increases.
6. It is better to give pain medicine around the clock (on a schedule) rather than only when needed.
7. Treatments other than medications (such as massage, heat, relaxation) can be effective for relieving pain.
8. Pain medicine can often interfere with breathing.
9. Patients are often given too much pain medicine.

Figure 1- A comparison of the knowledge subscale scores on the Pain Experience Scale of pain-free patients (N=126) to patients with cancer-related pain (N=165). Each bar represents the mean ± S.E.M. with statistically significant differences ($p<0.05$) indicated by *.

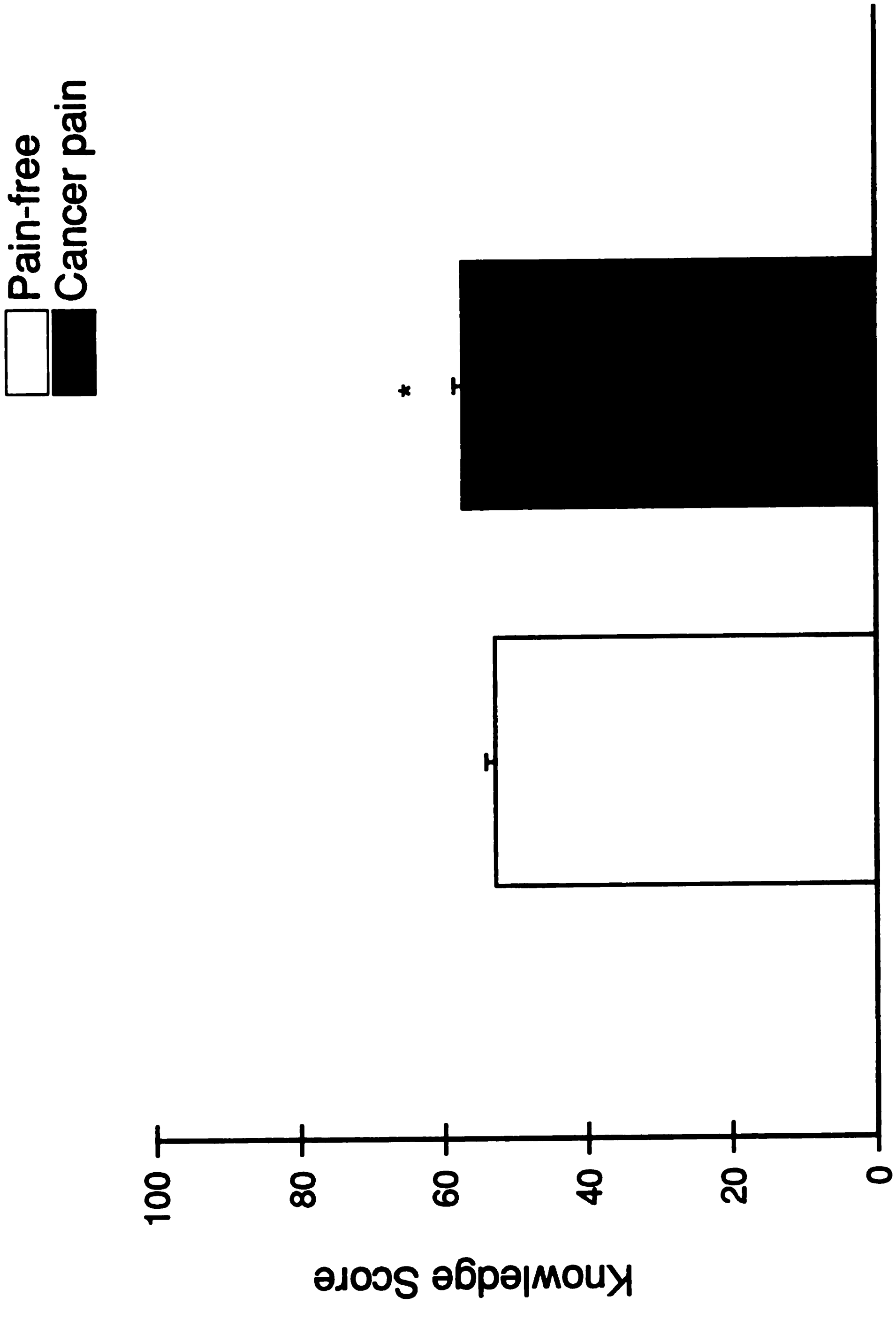

Pain-free
Cancer pain
Knowledge Score
100
80
60
40
20
0
*

Figure 2- A comparison of the knowledge subscale scores on the Pain Experience Scale of caregivers of pain-free patients (N=33) to caregivers of patients with cancer-related pain (N=72). Each bar represents the mean ± S.E.M. with statistically significant differences ($p<0.05$) indicated by *.

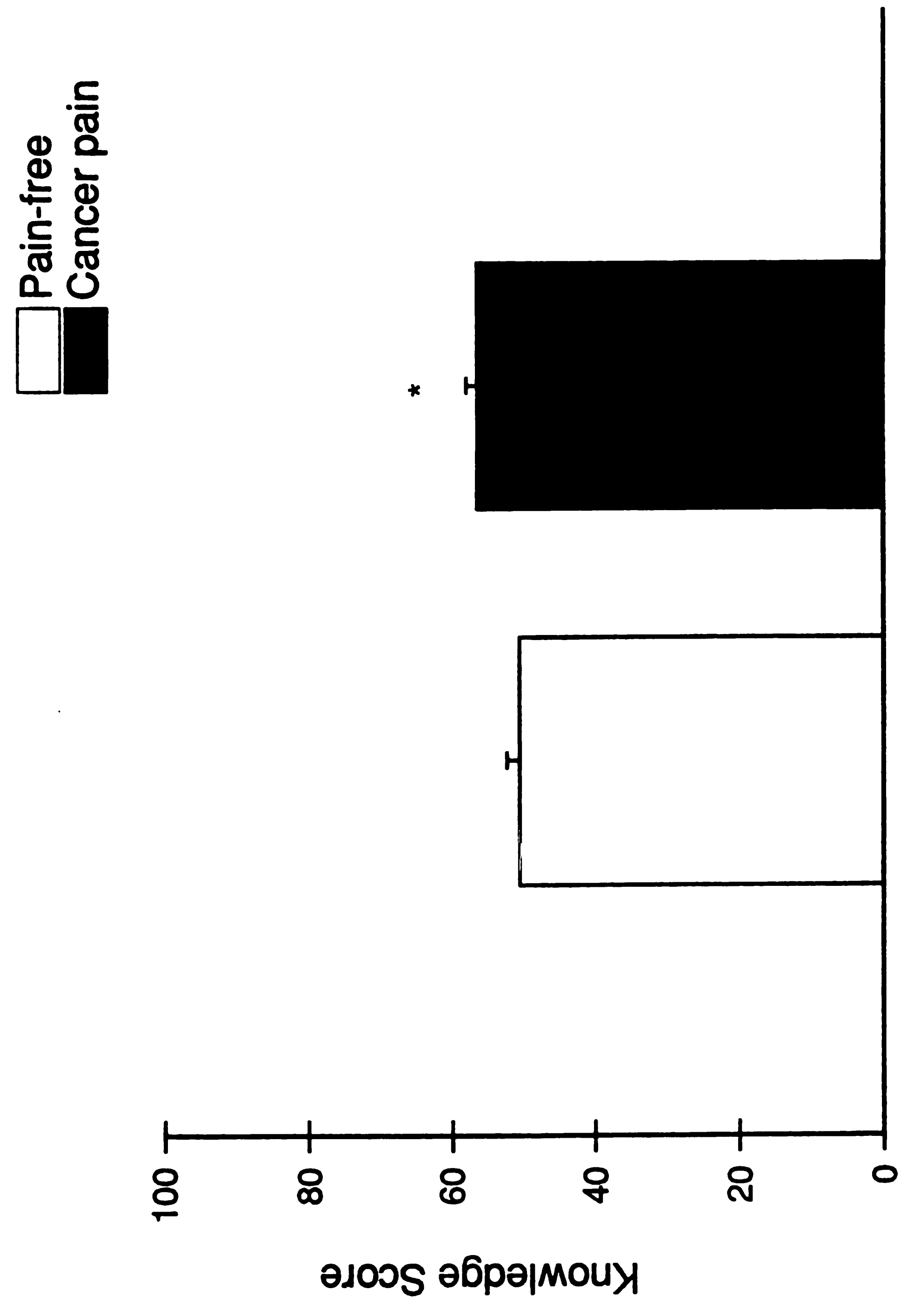

Pain-free
Cancer pain
*
Knowledge Score
100
80
60
40
20
0

Figure 3- A comparison of the knowledge subscale scores on the Pain Experience Scale of patients with cancer-related pain (N=64) and their caregivers (N=64). Each bar represents the mean ± S.E.M. with statistically significant differences (p<0.05) indicated by *.

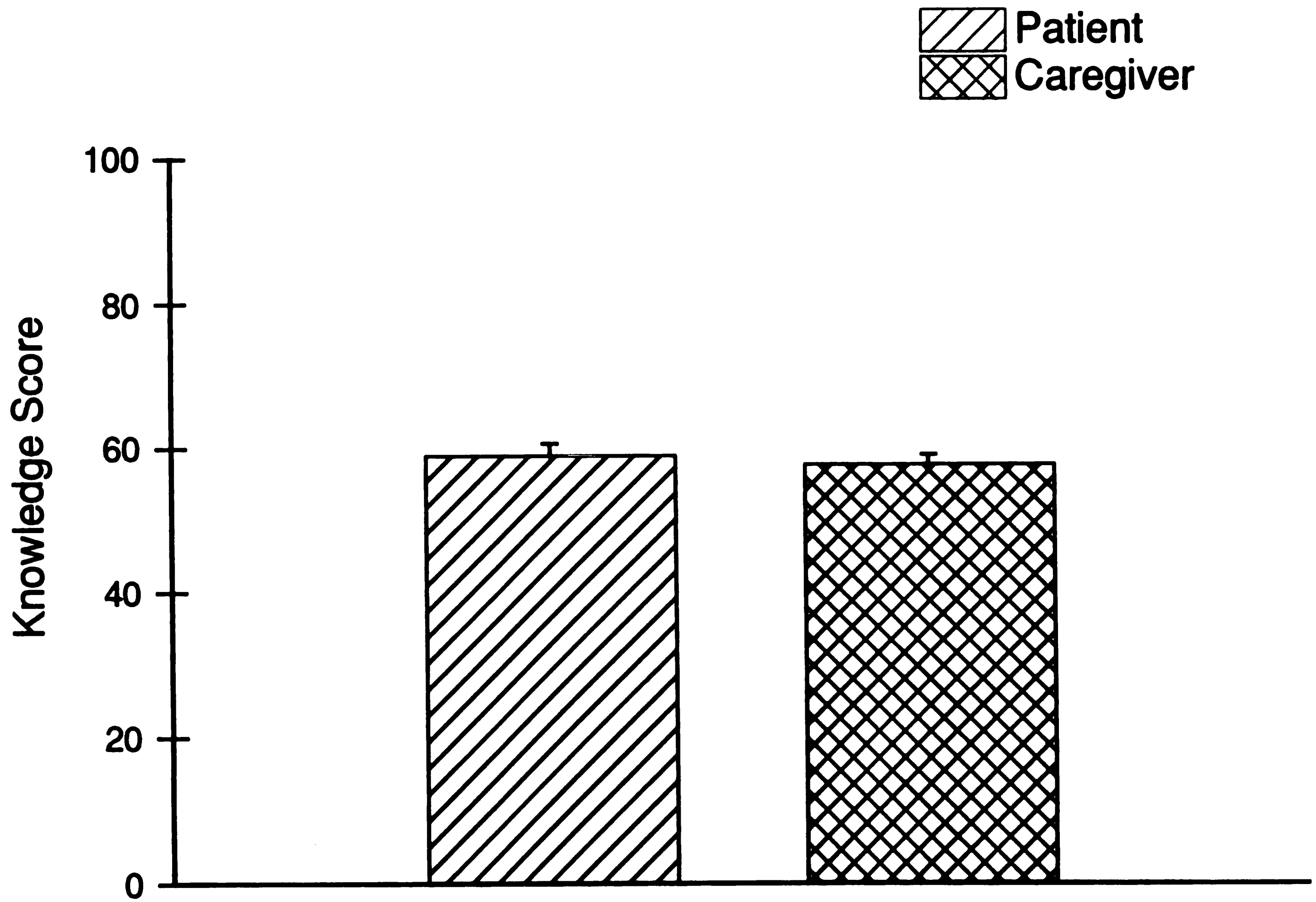

Patient
Caregiver
Knowledge Score
100
80
60
40
20
0

Figure 4- A comparison of the experience subscale scores on the Pain Experience Scale of patients with cancer-related pain (N=51) and their caregivers (N=51). Each bar represents the mean ± S.E.M. with statistically significant differences ($p<0.05$) indicated by *.

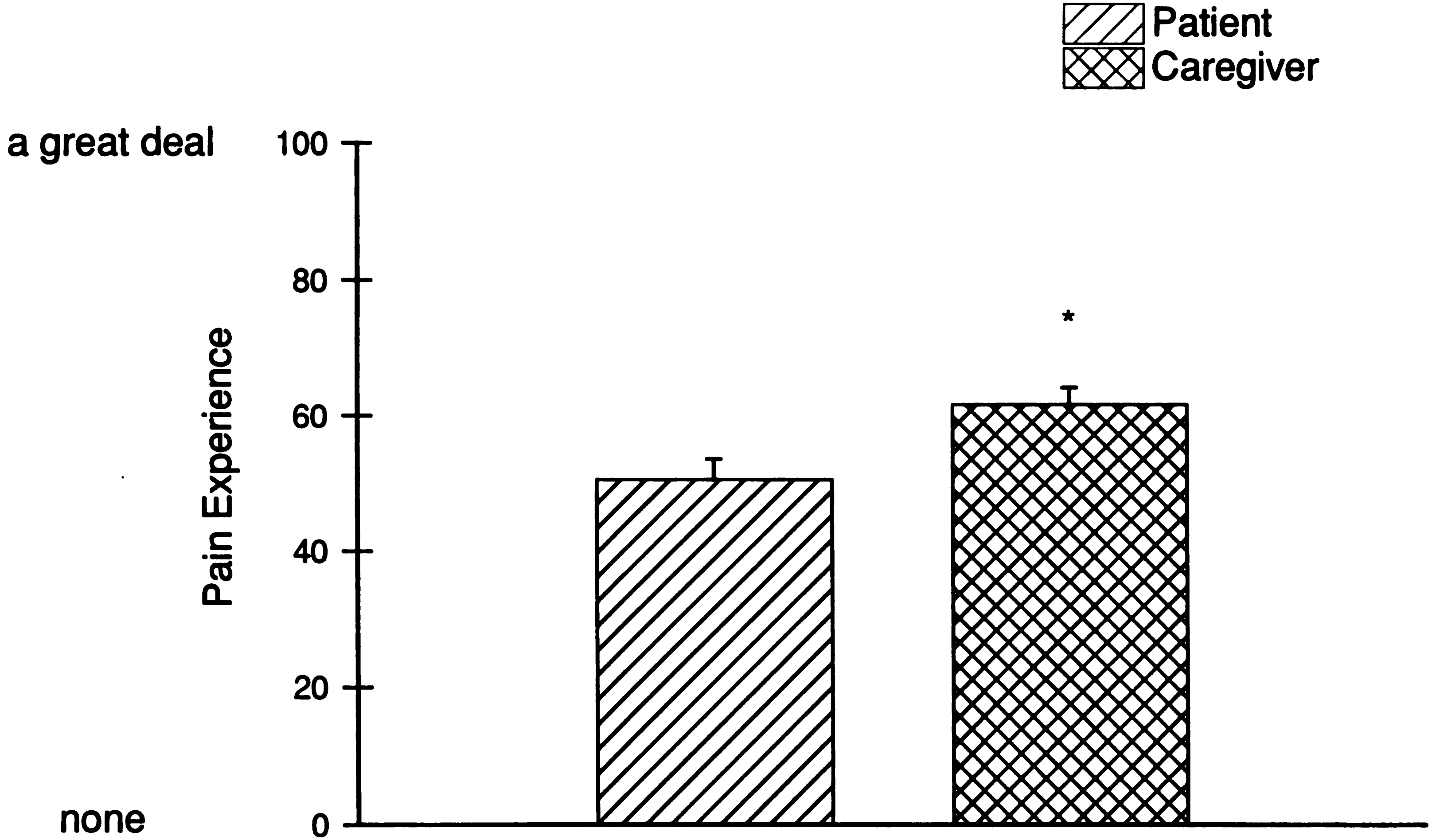

Patient
Caregiver
a great deal
none
Pain Experience
100
80
60
40
20
0
*

Figure 5- A comparison of pain intensity rating from the Pain Experience Scale of patients with cancer-related pain (N=70) and their caregivers (N=70). Each bar represents the mean ± S.E.M. with statistically significant differences ($p<0.05$) indicated by *.

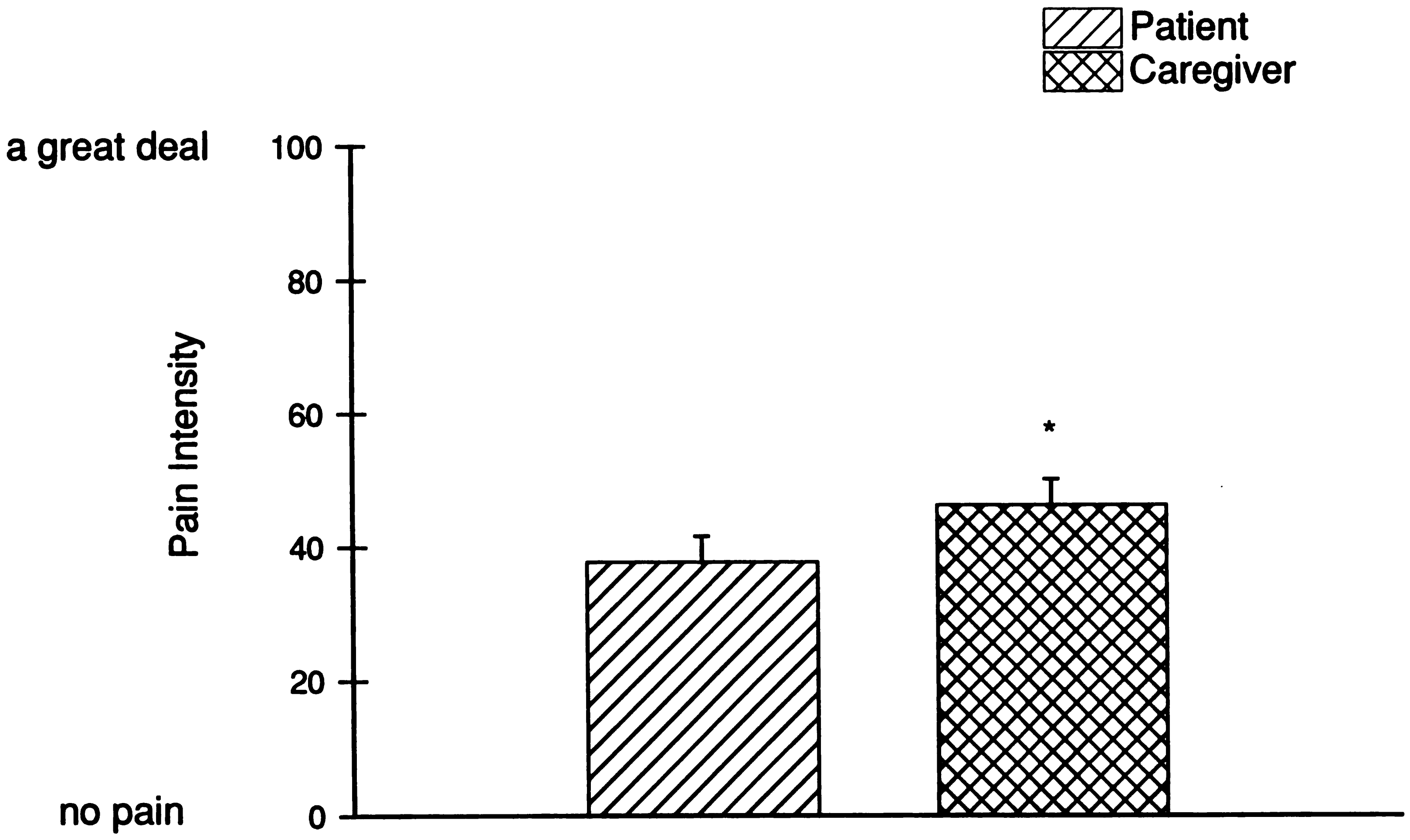

Patient
Caregiver
a great deal
Pain Intensity
no pain
100
80
60
40
20
0
*

Figure 6- A comparison of the pain relief rating from the Pain Experience Scale of patients with cancer-related pain (N=65) and their caregivers (N=65). Each bar represents the mean ± S.E.M. with statistically significant differences ($p<0.05$) indicated by *.

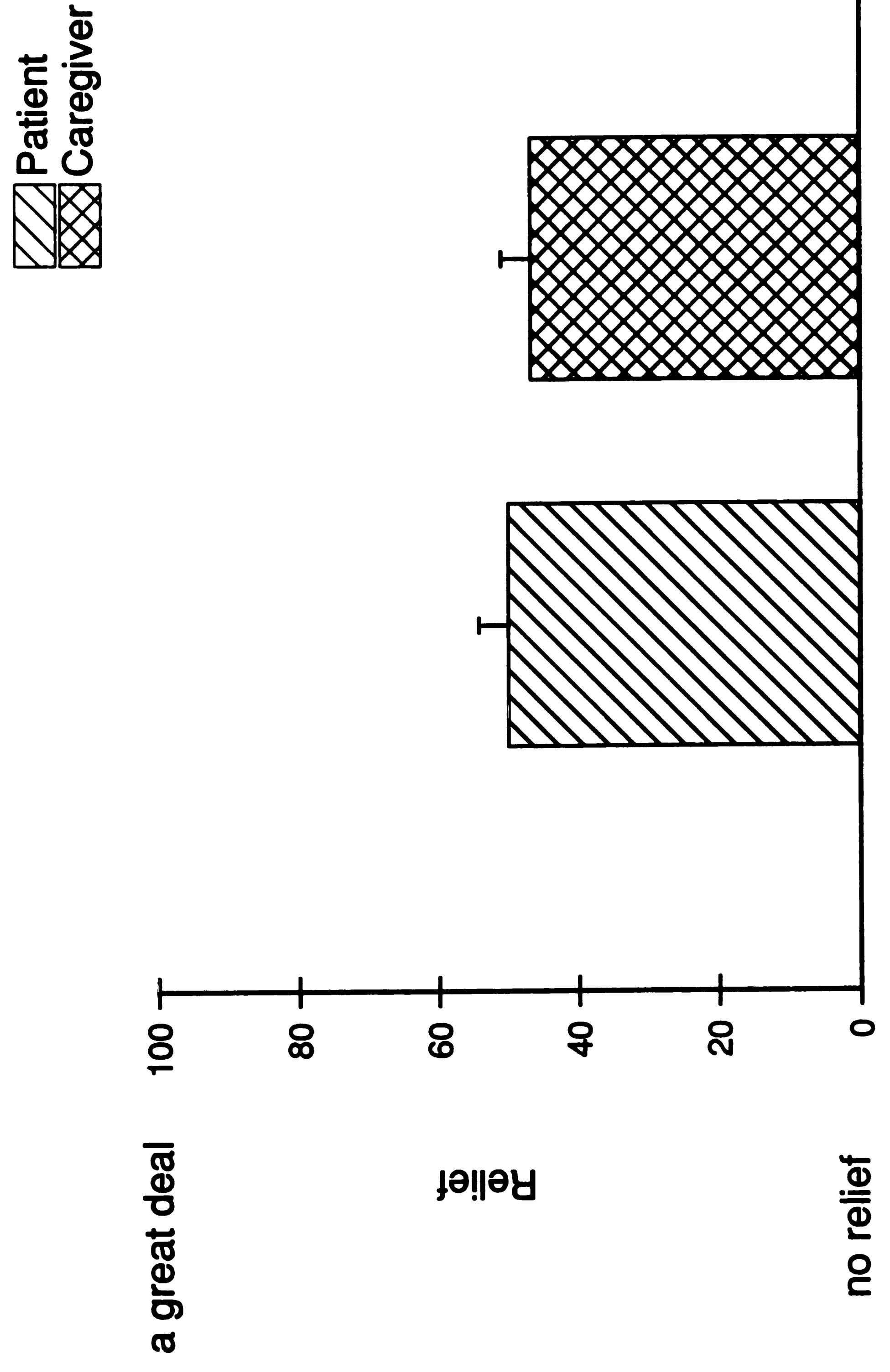

a great deal
Relief
no relief
100
80
60
40
20
0
Patient
Caregiver

Figure 7- A comparison of the patient distress rating from the Pain Experience Scale of patients with cancer-related pain (N=69) and their caregivers (N=69). Each bar represents the mean ± S.E.M. with statistically significant differences ($p<0.05$) indicated by *.

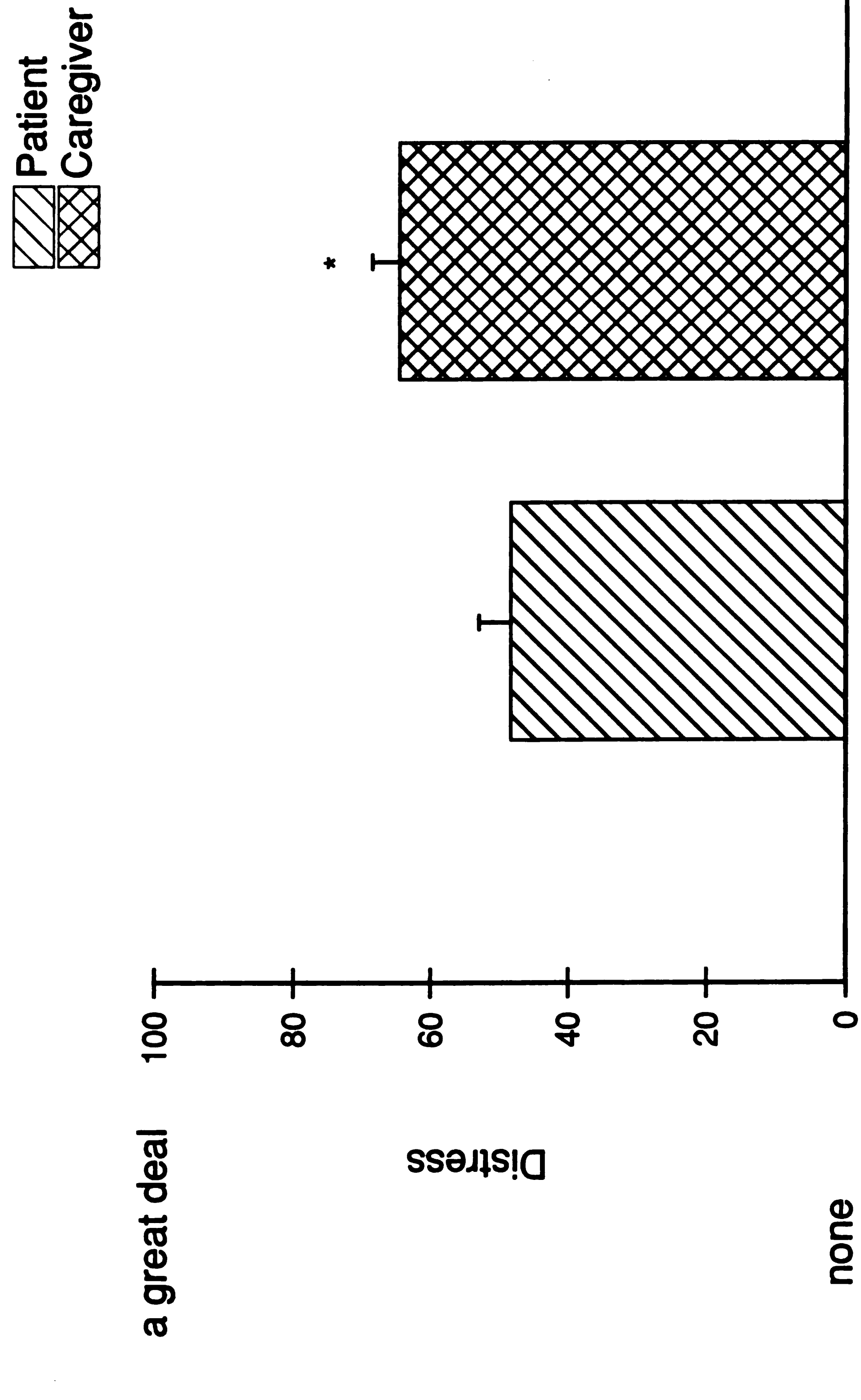
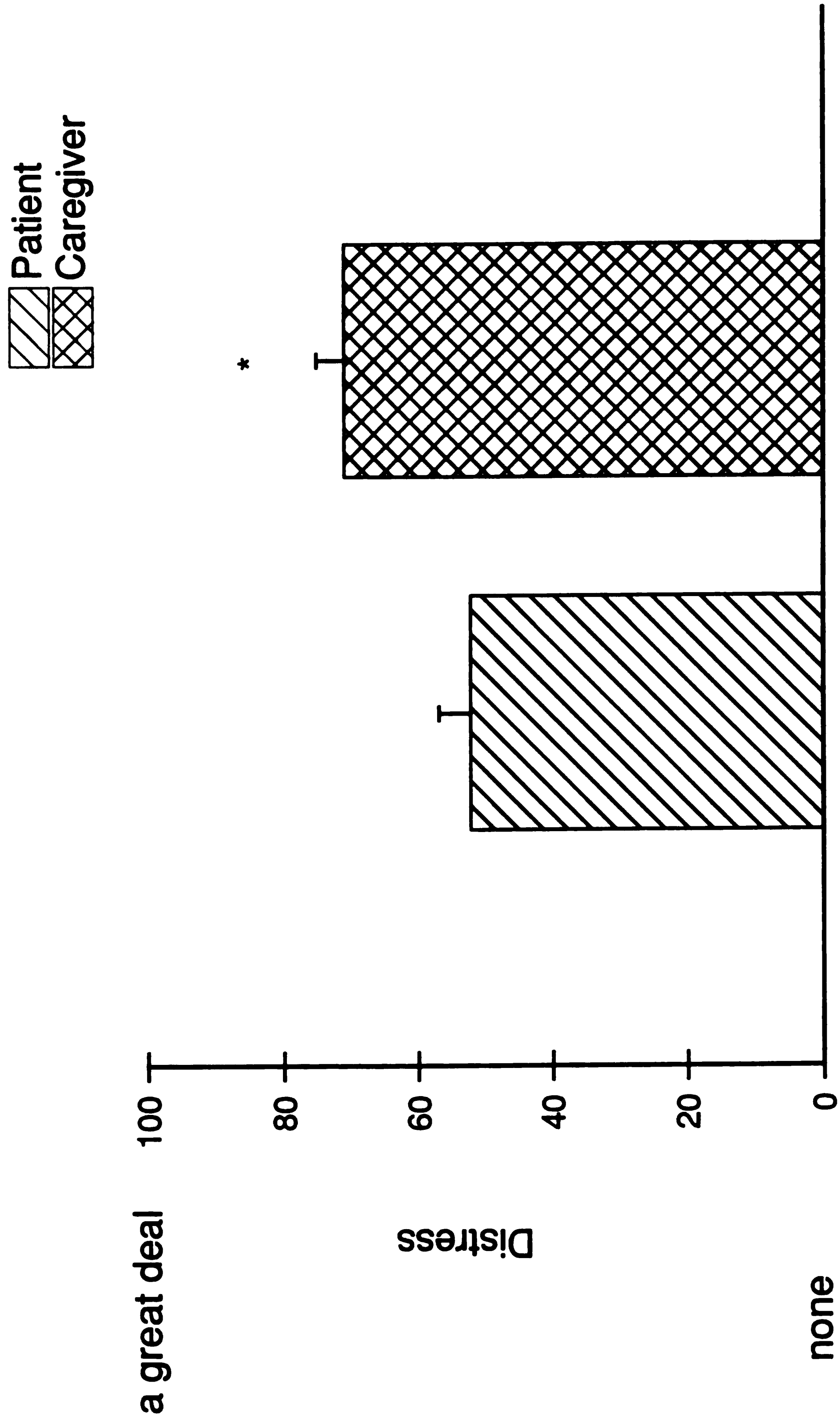

a great deal
Distress
none
100
80
60
40
20
0
*
▨ Patient
▩ Caregiver

Figure 8- A comparison of the caregiver distress rating from the Pain Experience Scale of patients with cancer-related pain (N=66) and their caregivers (N=66). Each bar represents the mean ± S.E.M. with statistically significant differences ($p<0.05$) indicated by *.


Patient
Caregiver
*
100
80
60
40
20
0
a great deal
Distress
none

Appendix A

Patient Pain Experience Scale

(Knowledge of Pain)

PAIN EXPERIENCE SCALE

Below are a number of statements about cancer pain and pain relief. Please an X on the line to indicate your response.

Your Understanding of Pain

1. Cancer pain can be effectively relieved.

   disagree ________________________________ agree

2. Pain medicines should be given only when pain is severe.

   disagree ________________________________ agree

3. Addiction refers to a person's desire to use drugs for their psychic effects rather than for medical use of relieving pain. Most cancer patients on pain medicines will become psychologically addicted to the medicines over time.

   disagree ________________________________ agree

4. Drug dependence means that a person would go through withdrawal if a pain medicine was stopped. Most cancer patients on pain medicines will become physically dependent on the medicines over time.

   disagree ________________________________ agree

5. It is better to give the lowest amount of medicines possible early on so that larger doses will be available later if pain increases.

   disagree ________________________________ agree

6. It is better to give pain medications around the clock (on a schedule) rather than only when needed.

   disagree ________________________________ agree

7. Treatments other than medications (such as massage, heat, relaxation) can be effective for relieving pain.

   disagree ________________________________ agree

PAIN EXPERIENCE SCALE (continued)

---

8. **Pain medicines can often interfere with breathing.**

disagree ______________________________________ agree

9. **Patients are often given too much pain medicine.**

disagree ______________________________________ agree

10. **Have you had cancer-related pain in the past month?** ____ Yes ____ No

***IF YES*, please complete questions 11 through 14 below.**

Appendix B

Patient Pain Experience Scale

(Experience of Pain)

Your Experience with Pain

11. How much pain are you currently having?

no pain ____ a great deal

12. How much pain relief are you currently receiving?

no relief ____ a great deal

13. How distressing is your pain to you?

none ____ a great deal

14. How distressing is your pain to your family members?

none ____ a great deal

Appendix C

Demographic Questionnaires

(Patient Information and Family Information)

PATIENT INFORMATION

1. Your Age: ____

2. ____ Female ____ Male

3. Do you live alone? ____ Yes ____ No

4. What is your current marital status?

____ Married/Partnered
____ Widowed
____ Divorced
____ Separated
____ Never Married
____ Not married but living together

5. Circle the highest grade or year you completed in regular school, vocational school, college, or graduate professional training?

Grade School
1 2 3 4 5 6 7 8

High School
9 10 11 12

College
13 14 15 16

Graduate School
17 18 19 20 21 22 >22

6. Circle the number that best describes your ethnic group:

1 American Indian
2 Asian or Pacific Islander
3 Black
4 Caucasian/White
5 Eurasian
6 Hispanic
7 Mixed Ethnic Background
8 Other (specify)____________

7. What is your current employment status?

____ Full-time
____ Part-time
____ Self-employed
____ Homemaker
____ Retired
____ Unemployed due to pain
____ Unemployed for other reasons
____ Disability

8. What is the purpose of your present cancer treatment?

____ Cure my disease
____ Control my disease
____ Don't know the purpose
____ Treat the symptoms associated with my disease
____ Other (specify) ______________

FAMILY INFORMATION

---

1. Your Age: ____

2. ____ Female ____ Male

3. Please circle the letter that best describes your relationship to the patient:

   a Spouse/Partner
   b Significant other
   c Child
   d Sibling
   e Parent
   f Other relative (specify) ____________________
   g Neighbor
   h Friend
   i Other (specify) ____________________

4. What is your current marital status?

   1 Married/Partnered
   2 Widowed
   3 Divorced
   4 Separated
   5 Never Married
   6 Not married but living together

5. Circle the highest grade or year you completed in regular school, vocational school, college or graduate professional training?

   Grade School
   1 2 3 4 5 6 7 8

   High School
   9 10 11 12

   College
   13 14 15 16

   Graduate School
   17 18 19 20 21 22 > 22

6. Circle the number that best describes your ethnic group:

   1 American Indian
   2 Asian or Pacific Islander
   3 Black
   4 Caucasian/White
   5 Eurasian
   6 Hispanic
   7 Mixed Ethnic Background
   8 Other (specify) ____________________

FAMILY INFORMATION (continued)

---

7. Please circle your current employment status:

a	Full-time	d	Retired
b	Part-time	e	Leave of Absence
c	Unemployed	f	Other (Specify) ____________________

8. If your employment status has changed due to your family member's cancer or its treatment, please describe:

____

____

9. If you are currently employed, have you lost wages, salary or benefits due to caring for, taking your relative to treatment, or helping in other ways?

____ Yes ____ No ____ Not Employed

Appendix D

Medical Record Review Form

ID Number ______107

MEDICAL RECORD REVIEW
(Pain Survey)

Date of Diagnosis: ____/____/19____

Please circle the number or numbers to indicate your answers to the following:

Diagnosis:

1 Breast
2 Colon
3 Head & Neck
4 Hodgkins
5 Acute Leukemia
6 Lung
7 Malignant Melanoma
8 Non-Hodgkins Lymphoma
9 Ovarian
10 Prostate
11 Other (specify) ____________

Metastatic Sites:

1 None
2 Bone
3 Brain
4 Liver
5 Lung
6 Lymph Nodes (______/______)
7 Peritoneum
8 Other (specify) ____________

Previous Therapy:

1 Surgery
2 XRT
3 Chemotherapy
4 Biotherapy
5 Hormonal Therapy

Type of Surgery:

1 None
2 Mastectomy
3 Nephrectomy
4 Radical Head/Neck
5 Theracotomy
6 Other ____________

Current Therapy:

1 XRT
2 Chemotherapy
3 Biotherapy
4 Hormonal Therapy

Reason for Current Therapy:

1 Cure (including adjuvant)
2 Control
3 Palliation
4 Other ____________

Has the patient ever received any of the following drugs as part of their chemotherapeutic protocol (do not include the decadron given to prevent nausea)?

1 Steroids (Prednisone, Decadron)
2 Vincristine
3 Vinblastine (Velban)
4 Vindesine

Appendix E

Caregiver Pain Experience Scale

(Knowledge of Pain)

PAIN EXPERIENCE SCALE

Below are a number of statements about cancer pain and pain relief. Please make an X on the line to indicate your response.

Your Understanding of Pain

1. Cancer pain can be effectively relieved.

   disagree ____ agree

2. Pain medicines should be given only when pain is severe.

   disagree ____ agree

3. Addiction refers to a person's desire to use drugs for their psychic effects rather than for medical use of relieving pain. Most cancer patients on pain medicines will become psychologically addicted to the medicines over time.

   disagree ____ agree

4. Drug dependence means that a person would go through withdrawal if a pain medicine was stopped. Most cancer patients on pain medicines will become physically dependent on the medicines over time.

   disagree ____ agree

5. It is better to give the lowest amount of medicines possible early on so that larger doses will be available later if pain increases.

   disagree ____ agree

6. It is better to give pain medications around the clock (on a schedule) rather than only when needed.

   disagree ____ agree

7. Treatments other than medications (such as massage, heat, relaxation) can be effective for relieving pain.

   disagree ____ agree

PAIN EXPERIENCE SCALE (continued)

8. Pain medicines can often interfere with breathing.

   disagree ______________________________ agree

9. Patients are often given too much pain medicine.

   disagree ______________________________ agree

10. Has the patient had cancer-related pain in the past month?

    ____ Yes ____ No

    IF YES, please complete questions 11 through 14 below.

Appendix F

Caregiver Pain Experience Scale

(Experience of Pain)

Your Experience with Pain

11. How much pain is the patient currently having?

no pain ____ a great deal

12. How much pain relief is the patient currently receiving?

no relief ____ a great deal

13. How distressing is the patient's pain for the patient?

none ____ a great deal

14. How distressing is the patient's pain to you?

none ____ a great deal

Appendix G

Karnofsky Performance Scale

INSTRUCTIONS: PLEASE CIRCLE THE NUMBER THAT BEST DESCRIBES YOUR ABILITIES AT THE PRESENT TIME.

I feel normal; I have no complaints or symptoms.	100
I am able to carry on normal activities; I have minor signs or symptoms of my illness.	90
It takes a bit of effort to engage in my normal activity	80
I can care for myself, but am unable to carry on normal activity or to do active work.	70
I require occasional assistance, but am able to care for most of my personal needs.	60
I require a considerable amount of assistance and frequent medical care.	50
I require special care and assistance.	40
I feel severely disabled and need to be hospitalized.	30

Appendix H

Descriptive Numeric Rating Scales of Pain Intensity and Duration

5. Your current cancer-related pain intensity:

Pain Scale

0	1	2	3	4	5	6	7	8	9	10
none		mild			moderate			severe		excruciating

a. Choose the number from the scale above which best describes your degree of cancer-related pain for each of the following, and place it in the space provided:

_______ your pain right now
_______ your current average daily pain
_______ your current pain at its worst
_______ your current pain at its least

b. **How many days out of a typical week do you currently experience significant cancer-related pain (pain that interferes with your mood and/or activities)?**

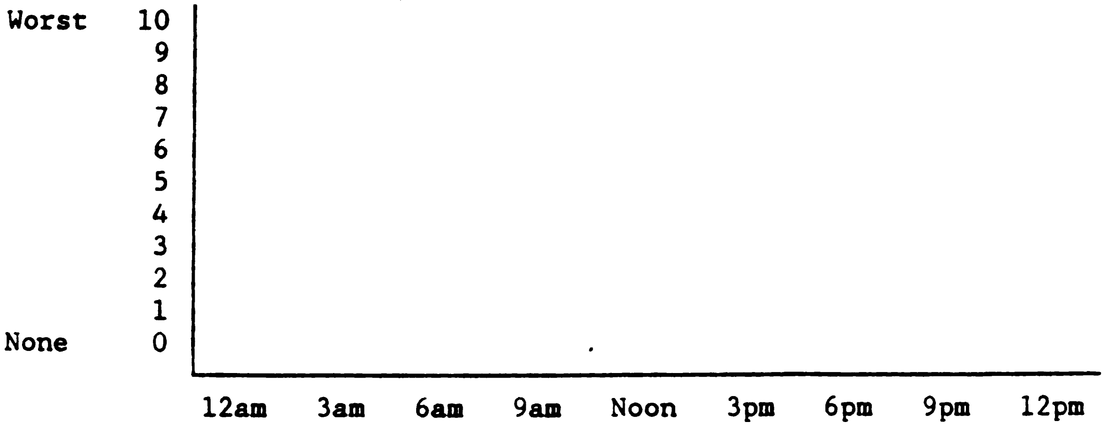
_______ **(enter how many days -- 0 to 7)**

c. **On those days where you have significant cancer-related pain, how many hours of the day does it currently last?**

_______ **(enter how many hours -- 0 to 24)**

6. **How does your cancer-related pain change during a typical day? On the graph below, for each time of day indicate the severity of your pain (10 indicates the worst pain you have ever had).**

PAIN INTENSITY



Appendix I

Informed Consent Form

(Patient)

CHR APPROVED
JUL 1 2 1991
APPROVAL EXPIRES
5/15/92

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
DEPARTMENT OF PHYSIOLOGICAL NURSING
CONSENT TO BE A RESEARCH SUBJECT
(PATIENT)

A. PURPOSE AND BACKGROUND:

Christine Miaskowski, R.N., Ph.D. and Suzanne Dibble, R.N., D.N.Sc. and their associates are conducting a study to learn about cancer-related and non-cancer related pain and its effects on adult ambulatory cancer patients and their caregivers. Because I am being treated for cancer, I am being asked to participate in this study.

B. PROCEDURES:

If I agree to be in this study, the following will happen:

1. I will be asked to identify a caregiver who comes to the clinic/doctor's office with me, and this person will also be asked to participate in this study.

2. One of the investigators or their nurse associates will ask me to respond to questionnaires about my health and any pain I may have experienced. It will take approximately 60 minutes to complete these questionnaires.

3. If I have experienced any pain, the investigator or nurse associate will ask me to respond to another questionnaire packet about the pain. I can complete these questionnaires in the clinic/doctor's office, or I can take it home to complete and to bring back at my next appointment. It will take approximately 45 minutes to complete this questionnaire packet.

4. The investigators or their associates will check my medical records to gather information about my cancer and its treatment and any health problems I may have experienced.

C. RISKS/DISCOMFORTS:

1. Participation in research may result in a loss of privacy; however, study records will be kept as confidential as is possible. No individual identities will be used in any reports or publications resulting from this study. Study information will be coded and kept in locked files at all times. Only the investigators will have access to the files.

2. Participation in this study will not interfere with my appointment, but it may add on time to the visit. To minimize this time, if I am asked to complete the second questionnire, I may take it home to complete there and return it during my next appointment.

3. Some of the questions on the questionnaires may make me uncomfortable or upset, but I am free to decline to answer any questions I don't wish to.

D. BENEFITS:

There may be no direct benefit to me from participating in this study. It is hoped that the information gained from the study will help with the identification and treatment of pain in future cancer patients.

E. ALTERNATIVES:

If I choose not to participate in this study, I will receive all my regular care, but I would not need to answer the questionnaires.

F. COSTS:

There will be no costs to me as a result of taking part in the study.

G. REIMBURSEMENT:

I will not be reimbursed for participating in this study.

H. QUESTIONS:

This study has been explained to me by Dr. Miaskowski or ________________________ and my questions were answered. If I have other questions about the study, I may call Dr. Miaskowski at (415) 476-9407, Dr. Dibble at (415) 476-5685, or

____________________________ at ____________________.

I. CONSENT:

I have been given copies of this consent form and the Experimental Subject's Bill of Rights to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. I have the right to decline to participate or to withdraw at any point in this study without jeopardy to my nursing or medical care.

If I wish to participate, I should sign below:

________________	________________________________	________________________
Date	Subject's Signature	Telephone Number
________________	________________________________	
Date	Witness' Signature	

PAIN/CONS
6/26/91

Appendix J

Pain Questions

28. ____ sociable
____ detached

29. ____ concrete
____ abstract

30. ____ who
____ what

31. ____ impulse
____ decision

32. ____ party
____ theater

33. ____ build
____ invent

34. ____ uncritical
____ critical

35. ____ punctual
____ leisurely

36. ____ foundation
____ spire

37. ____ wary
____ trustful

38. ____ changing
____ permanent

39. ____ theory
____ experience

40. ____ agree
____ discuss

41. ____ orderly
____ easygoing

42. ____ sign
____ symbol

43. ____ quick
____ careful

44. ____ accept
____ change

45. ____ known
____ unknown

In the past ***month***, have you experienced pain related to your cancer or cancer treatment?

____ Yes ____ No

In the past ***month***, have you experienced pain from a cause other than your cancer or cancer treatment?

____ Yes ____ No

PLEASE RETURN THIS QUESTIONNAIRE TO YOUR NURSE WHEN COMPLETED.

If you answered YES to either or both of the above questions, your nurse will give you an additional questionnaire to complete. Please complete these questionnaires now or bring them back at your next scheduled appointment.

Appendix K

Informed Consent Form

(Caregiver)

CAREGIVER

CHR
APPROVED
JUL 12 1991
APPROVAL EXPIRES
5/15/92

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
DEPARTMENT OF PHYSIOLOGICAL NURSING
CONSENT TO BE A RESEARCH SUBJECT
(CAREGIVER)

A. PURPOSE AND BACKGROUND:

Christine Miaskowski, R.N., Ph.D. and Suzanne Dibble, R.N., D.N.Sc. and their associates are conducting a study to learn about cancer related and non-cancer related pain and its effects on adult ambulatory cancer patients and their caregivers. Because I am a caregiver for a person being treated for cancer, I am being asked to participate in this study.

B. PROCEDURES:

If I agree to be in this study, the following will happen:

One of the investigators or their nurse associates will ask me to respond to questions about my caregiving role and its effect on me, and about any pain experienced by the person for whom I am providing care. It will take approximately 60 minutes to complete these questionnaires.

C. RISKS/DISCOMFORTS:

1. Participation in research may result in a loss of privacy; however, study records will be kept as confidential as is possible. No individual identities will be used in any reports or publications resulting from this study. Study information will be coded and kept in locked files at all times. Only the investigators will have access to the files.

2. Participation in this study may add to the time spent in the clinic/doctor's office for the patient's regular visit.

3. Some of the questions on the questionnaires may make me uncomfortable or upset, but I am free to decline to answer any questions I don't wish to.

D. BENEFITS:

There may be no direct benefit to me or to the patient from participating in this study. It is hoped that the information gained from the study will help doctors and nurses to assist future caregivers who are dealing with cancer patients and their pain.

E. ALTERNATIVES:

If I choose not to participate in this study, the patient will receive all regular care, but I would not need to answer the questionnaires.

F. COSTS:

There will be no costs to me as a result of taking part in the study.

G. REIMBURSEMENT:

I will not be reimbursed for participating in this study.

H. QUESTIONS:

This study has been explained to me by Dr. Miaskowski or ______________________ and my questions were answered. If I have other questions about the study, I may call Dr. Miaskowski at (415) 476-9407, Dr. Dibble at (415) 476-5685, or

____________________________ at ____________________.

I. CONSENT:

I have been given copies of this consent form and the Experimental Subject's Bill of Rights to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. I have the right to decline to participate without jeopardy to the patient's medical or nursing care.

If I wish to participate, I should sign below.

________________	________________________________	______________________
Date	Caregiver's Signature	Telephone Number
________________	________________________________	
Date	Witness' Signature	